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ABSTRACT

This document consists of the first three issues of a new newsletter concerning people who are deaf-blind. Issues present substantive articles, news on technical assistance in various areas, book reviews, and conference information. The following articles are included: (1) "Rationale for Editorial Policy on Terminology" (John W. Reiman), which explains the newsletter's policy of requiring a clear definition of the population being referenced; (2) "Doors" (Joyce Ford), in which a mother recounts the reactions of her deaf-blind son's nondisabled classmates when he moved to another school; (3) "Teaching Students Who Are Deaf-Blind and Cognitively Disabled To Effectively Communicate Choices During Mealtime" (Carole R. Gothelf and others); (4) "The National Information Clearinghouse on Children Who Are Deaf-Blind" (Bruce Bull); (5) "Blue Chair Time" (Joyce Ford); (6) "Can Inclusive Education Work for Students Who Are Deaf-Blind?" (Lori Goetz); (7) "Assessing the Instructional Environment To Meet the Needs of Learners with Multiple Disabilities Including Students Who Are Deaf-Blind" (Bonnie L. Utley); (8) "DB-LINK: Concept to Clearinghouse" (Gail Leslie); (9) "Looking at Self-Stimulation in the Pursuit of Leisure" (Kate Moss); (10) "A Dangerous Misrepresentation of the Facts in the 15th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act" (Vic Baldwin); (11) "Family Fun Day--An Experience in Nature" (Barbara Cook); (12) "A Guide for Presenters at Interpreted Conferences" (Rhonda Jacobs and Richelle Hammett); and (13) "Cruising the Information Highway" (Randy Klumph). (DB)

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Deaf-Blind Perspectives

Volume 1, Issue 1 Fall 1993

Why Deaf-Blind Perspectives?

by
Bud Fredericks
Research Professor, Teaching Research

For more than 20 years the staff at Teaching Research have been involved with matters related to people who are deaf-blind. We provided technical assistance to the Northwest Regional Deaf-Blind Center, directed a number of demonstration projects funded by the federal government, and for the past few years provided technical assistance to the states and regions through TRACES. We conducted, together with the federal government, the National Symposium on Children and Youth Who Are Deaf-Blind. We have most recently formed a consortium with the American Association of the Deaf-Blind, the American Foundation for the Blind, Helen Keller National Center, and Perkins School for the Blind to establish DB-LINK, the National Information Clearinghouse On Children Who Are Deaf-Blind.

During all these activities we published newsletters, reports, made presentations, wrote chapters for books, and in general, tried to promulgate information. The National Deaf-Blind Bulletin Board of SpecialNet was established recently and is being managed by Teaching Research and the California Deaf-Blind Program.

Despite the amount of information being promulgated through these channels, we recognized that there were many issues, problems, concerns and different opinions about matters that affected those who are deaf-blind and their families which were not being adequately discussed in the existing printed periodicals. That such issues existed and needed a medium through which they could be comprehensively aired was amply demonstrated by the papers presented at the Hilton-Perkins National Conference and through the National Symposium on Children and Youth Who Are Deaf-Blind, sponsored by the federal government. We examined existing newsletters to determine whether any met the need that we perceived. We found them all to be quite parochial in their subject matter. For instance, the TRACES newsletter focused only on children and youth who are deaf-blind (birth to 21 years). The Helen Keller TAC newsletter targeted the transition years. We concluded that there was a need for a publication, such as Deaf-Blind Perspectives, that would span the entire age range from birth to senior citizen, and consider the heterogeneity of people who are deaf-blind, to include discussions about those who are deaf-blind and cognitively able and those who are deaf-blind and cognitively disabled.

We recognized that what we were considering had characteristics that were more journal-like than a newsletter. However, the effort and resources to undertake a journal publication at this time were not available, nor did we wish to ask readers to pay for the publication.

In order to finance Deaf-Blind Perspectives we decided to combine the resources of three entities: (a) Teaching Research currently publishes an eclectic newsletter that focuses on projects that Teaching Research staff are conducting. These range from early childhood special education programs to residential facilities for adults with disabilities who have severe behavior problems. Teaching Research agreed to contribute the resources of that newsletter to Deaf-Blind Perspectives. (b) In addition, TRACES agreed to contribute the resources it had for the publication of its newsletter with the understanding that a section of Deaf-Blind Perspectives would be devoted to

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TRACES matters. (c) DB-LINK agreed to the same arrangement. Thus the TRACES Newsletter will no longer be published as a separate entity nor will DB-LINK commence promulgating their own newsletter. In addition, Teaching Research will, during the next couple of years, cease the publication of its newsletter.

What type of articles do we foresee being published in Deaf-Blind Perspectives? We want the newsletter to focus on pertinent issues regarding people who are deaf-blind and those involved with them. An article that discusses the discrepancies between services available for adults who are cognitively able and those who are cognitively disabled might be appropriate. For instance, we know from previous discussions with adults who are deaf-blind that a disturbing issue is the availability of transportation to those who are deaf-blind and cognitively disabled whereas comparable transportation services are not available for those who are deaf-blind and cognitively able.

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Other articles might examine inclusion. We certainly have heard many opinions about inclusion and its merits and faults over the past few years. Articles representing the spectrum of opinions would be welcome. The range of subject matter of articles is endless - early intervention, transition, communication techniques, syndrome characteristics, parental concerns, etc. are all appropriate. We encourage controversy and discussion and will at times invite articles that will represent opposing views on topics. We want the newsletter to be perceived as a forum for ideas and discussion.

We encourage persons who are deaf-blind, parents of persons who are deaf-blind, and professionals to submit articles to Deaf-Blind Perspectives. The articles will be reviewed by a panel of editors and will be either accepted as is, accepted with suggested revisions, or rejected, based on the reviews of the editors. Quality will be the criterion for acceptance. Ideological positions will not be grounds for nonacceptance.

We believe that by presenting the diverse opinions that exist among those who are deaf-blind, their parents, and the professionals who are involved with them we shall begin to accept the differences that exist within the field and perhaps reconcile some of those differences. Thereby, we might help to build a discipline that is united in purpose and yet retains its diversity.

We look forward to publishing this newsletter. We wish it to be of high quality and welcome your suggestions and criticisms. Kudos are appreciated at any time.

Rationale For Editorial Policy On Terminology

by
John W. Reiman
Associate Research Professor, Teaching Research

The promotion of choice, inclusion, and self-determination for people who are disabled requires something from everyone. For those who write on matters related to such persons, the requirement is accuracy and precision.

Imprecise linguistic descriptions of people who are deaf-blind pervade contemporary literature. Do constructs from the vernacular of professionals like "dual sensory-impairment", "with deaf-blindness", and "the deaf-blind" serve the best interest of the people they attempt to describe? To dispute the use of such terminology is not to be pedantic and nitpicky, but to express concern about a real problem. In the paragraphs that follow, I will (a) provide examples of questionable terms and phrases, (b) comment on their possible negative effects, and (c) present an editorial policy for Deaf-Blind Perspectives that will invite greater precision in language used to characterize this population.

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Examples of Imprecise Terminology

The terminology in question assumes three primary forms. First, is the medical-model-inspired **pathologizing** variety with its deficit-based watchword, "impairment." "Dual sensory-impaired students", "hearing- and vision-impaired students", "sensory-impaired students", and a host of related descriptions of human beings that champion what is absent about a person and fail to describe what is present—such terms simply alert us to something about a person being wrong. Person-first language (e.g., "students with dual sensory impairments") is purported to address this problem by emphasizing the person first rather than the disability. Placing the person first, however, doesn't erase the negative associations invited by "impairment"—a term out of favor in most other areas of special education and rehabilitation.

Tugging at the heartstrings of potential contributors with misleading images ... does little to contribute to general understanding of people who are deaf-blind.

A variant on the pathologizing theme is the now popular "with deaf-blindness" (e.g., students with deaf-blindness). The "-ness" is a suffix that forms abstract nouns denoting quality and state (Random House Webster's College Dictionary - 1993). Is an abstract noun adequate for defining the population of people who are deaf-blind? Unfortunately, the abstraction's lack of precision invites creative connotations—the notion of affliction in this case. Combined hearing and vision loss are made to seem like an infirmity or ailment that someone ends up "with." Adversity, distress, hardship, and tribulation are implied. Understandably, some people who are deaf-blind hold contempt for this construct. Escaping disability-related stigma spawned by professionals' use of "with deaf-blindness" terminology, must be an additional and unwelcomed challenge.

A second form of questionable terminology is the **objectifying** variety. "Educators should prepare deaf-blind for..." and "...when the deaf-blind use interpreters" are two examples. Both completely omit the person reference making the human and the disability one and the same. Ironically, there is a twist to this one. On one hand, when hearing/sighted professionals in education and other fields use such language to describe children who are deaf-blind, charges of objectification and paternalism may be leveled. On the other hand, when numerous adults who are deaf-blind (many of whom belong to the American Association of the Deaf-Blind) refer to themselves or to each other, the same terminology deemed as objectifying above, becomes the opposite—validating and affirming. In this context, as a mark of respect and affirmation for community, linguistic, and cultural integrity, usages like "the deaf-blind are...," "some deaf-blind feel...," and "when Deaf-Blind want..." (note upper-case usage) are the norm.

Terminology of the **overgeneralizing** variety is the third form in question. To say that people who are deaf-blind uniformly think, feel, need, or want almost anything universally, is to discount the heterogeneity and enormous differences that characterize this population. These differences are pronounced in the multiplicity of gifts they contribute to the world, as well as the differences in their needs.. The de facto claim, for example, that "clients who are deaf-blind present with serious communication deficits" (drawn from a counseling context) is fallacious. Can an eighteen year-old Gallaudet University student who is deaf-blind (Ushers Type I) and, using interpreters, maintaining a 3.5 GPA, be viewed as having "serious communication deficits?" **Which** people who are deaf-blind is the question always begging an answer.

In short, the use of pathologizing, objectifying, and overgeneralizing terminology may compromise accuracy in describing people who are deaf-blind, and may erroneously homogenize such peoples' dissimilar characteristics and needs.

Possible Negative Effects of Such Terminology

Two possible effects come immediately to mind stemming from use of the terminology described above.

First, is it possible that professionals' use of the aforementioned terminology may lend fuel to others' inaccurate portrayals of people who are deaf-blind? A recent telemarketing campaign by a company contracted to raise funds for an agency related to people who are deaf-blind included the following among its categories for sponsorship:

- "Power of Communication" sponsors... who "open up the worlds of hearing and sight for persons who are deaf-blind."
- "Lift the Darkness" sponsors... who "help the curtains of communication be opened and the darkness lifted by the rays of awareness."

Tugging at the heartstrings of potential contributors with misleading images of "worlds

being opened" and "curtains lifted" does little to contribute to general understanding of people who are deaf-blind. Isn't it incumbent on us as professionals to forego pathologizing, objectifying, and overgeneralizing terminology in the interest of encouraging realistic and accurate portrayals? Mightn't our inaccurate terminology lend tacit support to the sale of images as above by modeling imprecision as acceptable?

A second negative effect of the foregoing terminology may be directly experienced by people who are deaf-blind. Amidst deficit-based characterizations across a wide range of print media, what amount of such negativity is directly experienced by the person who is deaf-blind? Imagine one's experience of being labeled in terms limited to what about one was weakened, damaged, injured, or deficient. Whether it be directly through auditorally, visually or tactually received information, or indirectly through the reflected pathos of mass culture, isn't it likely that such terminology does a disservice to the very people it seeks to describe?

As a hearing/sighted person, it would be presumptuous to assume I understood the magnitude of such terminology's negative impact. People who are deaf-blind are presumably affected in untold ways beyond those suggested above.

An Editorial Policy Inviting Greater Precision

Given the above, it shall be the editorial policy of Deaf-Blind Perspectives to require that manuscripts define in no uncertain terms, the population being referenced. The responsibility for defining which subset of people who are deaf-blind each article is referencing, shall remain with the writer (and editors), not the reader. Deaf-Blind Perspectives will edit submissions to reflect person-first language (e.g., "... who are deaf-blind") except in such cases where community, linguistic, or cultural integrity are being cited (e.g., American Association of the Deaf-Blind).

Development of this policy is motivated by the editors' wish to promote respectful relationships between people that honor and embrace individual differences. In the event a writer feels limited by such constraints, we welcome the opportunity for dialogue.

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Doors

by
Joyce Ford

Teaching skills to my son who is deaf-blind has often meant dissecting activities into tiny increments. To drink from a cup begins with locating it, grasping it, lifting it...and ten steps later taking a sip. Setting it down right-side up is another skill. Someone appropriately named it backwards chaining; the learning of a skill by chaining the sequence together backwards from the completion to the beginning.

So it was when it came to doors, except that the variety became greater. There are doors with doorknobs, and some with push-bars. There are sliding doors, folding doors, cabinet doors, car doors, and automatic doors in some places. Southwestern Idaho doesn't have many revolving doors...so I put that one aside for later. I focused on the plentiful assortment of doors that Riley encountered daily.

To fully consider the use of doors, I knew that our support services at McKinley Elementary School would be involved as they had been in other activities. Physical therapy would be concerned with Riley's upper body strength. Some doors are quite heavy. The therapist would plan exercises to develop those muscles. Occupational therapy would be troubled with the twisting wrist movement necessary for doorknobs, a motion quite unnatural for Riley. Speech therapy would emphasize signing words such as open, close, inside and outside into Riley's hands. The orientation and mobility instructor would worry about doors that others might dangerously open in Riley's path. Riley would need to be better with his cane. The Special Ed teacher would discuss data: 80% success on 50% of trials with 25% accuracy...a goal would be developed for Riley's Individual Education Plan.

In March of 1992, Riley left the McKinley Special Ed classroom and moved into a regular third grade classroom. Riley is the only deaf-blind student in our school district and one of the first students with severe disabilities to be included full time in a regular education classroom. He was now one of twenty-two third-graders, and the only one who didn't do doors. Fortunately, he was in the company of twenty-one eager 8-year-olds who were more than willing to overlook that. In their eyes, Riley could do lots of other things with them...eat lunch, play at recess, art, P.E., music, and library...all of which they felt were much more important than doors.

The following September the McKinley third-graders moved on to fourth grade, but it was without Riley. As a team, we had decided that Riley needed a full year of regular third grade before moving on. He started this new school year with twenty-one fresh and eager 8-year-old third-graders who were also willing to overlook the problem with doors.

The children willingly included Riley in their school day activities, but there were no friends when he came home. No one came to play on the weekends. They all lived too far away. Summer would be a long time to spend alone. By December, the decision had been made to move Riley to Valley View, our neighborhood school. Perhaps he would make friends here that would fill the void. The move would occur following Spring Break. Careful planning, attention, and support would be needed for staff and students since Riley would be the first child with severe disabilities to attend this school.

"Riley can't see and he can't hear...but he's just like us inside,"

To help with the move, four of Riley's classmates were asked to talk with the third-graders at Valley View. Ellie, a teacher who works with Riley, got them started by asking, "What is one thing that you would want other kids to know about Riley?"

They each answered differently with blatant honesty.

"You need to be gentle with him," one little girl answered. "He won't break, but you need to be gentle."

"Riley can't see and he can't hear...but he's just like us inside," one of the boys added.

The new third-graders began asking their own questions. "What didn't you like about having Riley in your class?"

"I didn't like it that he lived so far away. I can only see him at school and I would like to play with him at his house, but he doesn't live in our neighborhood so I can't go to see him."

"Why did Riley go to your school if he doesn't live in your neighborhood?"

"We don't know," Trisha responded matter-of-factly, "but we feel really lucky that he did."

"How did you feel when Riley first came to your class?"

Darren took this question. "I knew a little bit about Riley before because he was in my sister's class last year. I didn't mind helping him...we all wanted to help him. I just didn't know he would be my friend. Now when I think about my friends, I would have to say that Riley is one of my best friends." Tears came to his eyes. "I'm really going to miss him."

I hadn't planned on this. No one ever mentioned separation and loss. Inclusion was about good things...maybe this was good, but it didn't feel particularly good. Something had to be done to reassure these kids that they would always be an important part of Riley's life.

March 31, 1993 was Riley's last day at McKinley. Valley View honored Riley as their V.I.P. with a special bulletin board and a question and answer session. We met at the school at 12:30 and Riley was introduced in person. I brought some pictures and fielded their questions. Some of the questions were similar to the ones the McKinley students had asked a year ago: "Does he like to play Nintendo? What is his favorite color? Does he say words?" They were the questions kids who haven't been exposed to severe disabilities ask.

At 2:30 a farewell party was held at McKinley. I am a familiar face there, and I could tell the third-graders with all honesty and sincerity that they were very special people and that they would not be forgotten. I gave them each a little heart shaped pin with the "I love you" sign on it. Riley and I passed out chocolate cupcakes with mounds of white frosting and blue flowers. We saved the one he had stuck his thumb into several times for himself and carried it back to his desk where he promptly devoured it. I went to get paper towels.

A little girl approached me. "Crystal is crying," she said. "She doesn't want Riley to leave, and neither do I," she added tearfully.

"He is our friend. It won't be the same without him," another voice echoed.

I was surrounded by weeping children and I felt my own tears begin. They had all made cards for Riley...textured with colorful pipe cleaners, yarn, straws, beans, and fuzzy stickers. Each carried their message of friendship and wishes for new friends. Ben wrote Riley's name in braille. Trisha's began with a red velvet heart and contained a message to match it inside.

"You and Riley are going to leave, aren't you?" Crystal asked.

"I promise you we'll come back," I answered.

"But you're going to leave."

"Yes...we're going to leave. But when we leave, you can know in your hearts that you did something remarkable. Part of each of you

will go with us, and I hope that part of Riley and I will always stay with you. You taught all of us grown-ups some very important lessons." I kissed her forehead. "This is something we have to do."

There was another group of children on the other side of the room who were not tearful. They were speaking quietly and seriously to their teacher.

There are just so many types of doors. The dishwasher door opens down and the door on the car trunk opens up. The microwave has a button that must be pushed to open it's door. When you think about it, there is a lot to teach about doors.

The children across the room were solemn. They spoke their quiet wisdom in turns.

The oven door is hot sometimes and cool at other times. The refrigerator door is cold on the outside and colder on the inside. The back door has a storm door with a pet door. Some doors open to stairs and others don't. There is a lot to consider about doors.

They asked their teacher if another student from the self-contained classroom could come and be part of them. They told her they wanted that. They told her they needed that. She respectfully nodded in agreement.

And while I pondered the complexities of doors and my son's disabilities, Riley it seems, with his tremendous abilities had magically opened the heaviest and most difficult door of all.

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Teaching Students Who Are Deaf-Blind and Cognitively Disabled To Effectively Communicate Choices During Mealtime

by

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Individuals who are deaf-blind and have a cognitive disability may not effectively communicate their desires and choices even when provided with the opportunity to do so, in part because of their frequently limited communication skills. The ability of these individuals to make choices may be further constrained by instructional staff and caregivers, who anticipate their wishes and make choices for them. These caregivers and instructional staff may be acting with only the best intentions for these individuals, perhaps in the belief that they are unable to make a meaningful choice. Often, however, these individuals have not been taught how to make a choice. For students who are deaf-blind and cognitively disabled to achieve valued life outcomes, it is essential that they are able to effectively communicate personal choices.

Given the essential nature of the ability to communicate choice and the potential barriers to choice-making, it is necessary to focus on teaching students who are deaf-blind and cognitively disabled the process of making meaningful choices and to develop a flexible curriculum in which they have opportunities to practice making choices within the context of their daily routines. Mealtime is ideal for this instruction. It naturally occurs on a consistent, daily basis, in school, at home and in community environments. The act of communicating what one wants to eat or drink and receiving what one has chosen results in natural consequences that are highly motivating, thus reinforcing the power of clear communication.

The table that follows offers a set of practical guidelines for teaching students who are deaf-blind and cognitively disabled to make choices during mealtimes. It is offered as an aid to instructional staff and caregivers to il-

lustrate the ways in which a typical daily activity can be utilized to teach choice-making within the context of a natural routine. In addition, it has implications for how the skill can be increased in complexity as the student progresses. We offer this as an example that can be applied in other settings and activities, which include selecting something to do, choosing with whom to do it, choosing where to do it, choosing when to do i,t or choosing whether to do it at all (Brown & Gothelf, in preparation; Crimmins & Gothelf, in press)

Table 1

Choice-making Instruction		
Guiding Principle	**Example**	**Considerations**
People typically make choices in the environments in which the outcomes of their choice are available.	Choosing what to eat should take place where the student normally eats. Teaching choice-making in an artificial environment removes many of the naturally-occurring cues to the event.	Administrative policies and procedures should ensure that the choice-making process can take place. This may involve working with the cafeteria staff or revising lunch-time schedules.
The boundaries in which the choice-making activity takes place should be defined through the use of appropriate aids and cues. Providing boundaries minimizes the visual/motor and cognitive requirements of orienting and reaching.	A dycem placemat can be used to secure a cafeteria tray on a table, or on the lap tray of a student's wheel chair. A second dycem mat can be used to secure the plates and glasses on the tray. (Dycem is a non-slip plastic that is helpful in stabilizing objects on surfaces. It comes in reels or sheets that can be cut to size. It is portable, easily cleaned, inexpensive and available from adaptive aids catalogs).	If cafeteria trays are not available or necessary, the plates of food can be placed on a dycem mat directly on a table. For students with vision, the color of the dycem should be selected to provide contrast with the tray or table and the plates.
Individual preferences play an important role in enhancing motivation for the activity.	The student is presented with two entree samples, one at a time. The items from which a student is choosing should be two things which he or she is likely to want to eat.	Administrators should work with cafeteria staff to ensure that appropriate alternatives are made available. (E.g., if two hot meals are not available, a choice between a hot meal and sandwich, or between two sandwiches should be substituted.) Be aware that food preferences are influenced by a student's cultural and family background.
The student is made aware of the food through tactile/kinesthetic cues (guided or paired movements between the teacher and the student), visual, verbal, gestural and object cues. The teacher must assess the conditions that facilitate comprehension (e.g., with gestures, without gestures, etc.).	For each sample of food, the student is moved through touching the plate, touching the food, smelling the food, and tasting the food. A staff member will say the name of the food, sign it, and shape the student's hands to sign the name of the food.	The student's receptive vocabulary may be limited. Natural routines should be maintained within the normal context of mealtime in order to help the student comprehend the expectancies for his or her behavior.
Choices should be presented consistently in order to reinforce the physical structure within which choosing occurs. Placing the choices in the same locations in relation to the student's body each time they are presented helps the student to anticipate where the sample is likely to be.	The first sample is presented on the student's left, tasted with the left hand, and then removed. The second sample is then presented on the student's right, tasted with the right hand, and then removed. Care must be taken to ensure that the individual is not always choosing the sample on the right or the sample on the left.	The student's ability to reach, grasp, and manipulate utensils or the food itself, may be influenced by poor muscle tone, stability, or coordination, as well as limited visual functioning. Generally, proper postural alignment can be attained through the use of adaptive positioning equipment. Grasping and manipulating utensils can be assisted through the use of adaptive aids such as special spoons, plates with lips, or slant trays. (Campbell, 1987).

Continued

Table 1 continued

Choice-making Instruction

Guiding Principle	Example	Considerations
Establishing routines within instructional sequences enables the student to anticipate the next step and encourages self-initiated choice-making. A pause or time-delay in a sequence (hands in the lap) may serve as a prompt to the student to initiate an interaction or make a selection (Siegel-Causey & Ernst, 1989).	Both samples are then presented to the student. The student touches the left plate with the left hand, and the right plate with the right hand. As the student touches each sample, he or she is reminded of its name. The student is then directed to place both hands in his or her lap (using verbal and/or physical prompt as needed). The student is then instructed: *"It is time to pick what you want for lunch."* Language input should be provided at a level and in a mode that the student can comprehend.	If a student does not respond when the question is repeated, the teacher communicates: *"That's OK, if you don't want the meat or the rice, I'll ask you again soon."* Language input should be provided at a level and in a mode that the student can comprehend. The teacher should always return and provide the student with another opportunity and additional prompting if necessary.
Reliable communication of preference depends upon a foundation of consistent responses to the student's non-verbal behaviors. Non-verbal behaviors need to be acknowledged by the teacher on the assumption that the individual is attempting to communicate meaningful dialog. This provides a basis for communicating shared meanings (Guess, Benson, & Siegel-Causey, 1985; Williams, 1991).	The student chooses the desired food by touching one of the samples, by looking or facial gesture, by starting to eat, by vocal sounds and/or body movements, by signing or in any way indicating his or her preference.	If the student reaches for both, or neither, the teacher must repeat the previous procedure, and reinforce that the student must choose one sample. The teacher must acknowledge any form of communication. If the student repeatedly reaches for both, he should be given some of each for lunch.
Components of everyday routines should be utilized to establish correspondence between words and their meanings. Routines enable students to take an active part in the activity and to communicate with the teacher.	The staff signs *"finished"* for the undesired plate and moves the student through the sign *"finished"* and prompts the student to move the plate away.	Initially, the student may require the teacher to move his hands for him. Subsequently, the teacher and the student should cooperatively move their hands together, the student's hands riding on top of the teacher's. The teacher should pause in the pushing action, and allow the student to communicate a desire to continue by moving the teacher's hands.
In addition to establishing correspondence between words and their meanings, the process of systematically using routines in the choice-making process must be established.	The teacher signs *"eat"* and the name of the desired food, and prompts the student to do the same. This procedure must follow the previous one.	The teacher may choose other ways to communicate the same message, such as signing the student's name followed by the signs for *"wants to eat"* and the name of the food. Language input should be provided at a level and in a mode that the student can comprehend.
Contingent communicative behavior is reinforced by getting the requested item. The student communicates through an action or a signal to indicate his preference.	The student is served a full portion of the food that was selected.	The student must join the cafeteria line to obtain the full portion of food.

Table adapted from Gothelf, C.R., Crimmins, D.B., Mercer, C.A., & Finocchiaro, P.A., (in press). Teaching choice-making skills to students with dual sensory impairments. TEACHING Exceptional Children, reprinted by permission of the editor.

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DB - LINK

The National Information Clearinghouse On Children Who Are Deaf-Blind

by
Bruce Bull
Assistant Professor, Teaching Research

In the United States today, a heterogeneous group of roughly 7500 children (birth through 21 years) who are deaf-blind, many of whom have additional disabilities, experience considerable unmet needs. For the general public, professionals, and parents to understand and respond intelligently to these needs, they must have access to reliable and well-organized information.

To address the critical need for a systematic approach to information sharing and dissemination, the Department of Education, Office of Special Education Programs, has awarded a cooperative agreement to the Teaching Research Division of Western Oregon State College to establish DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind). Funded in October 1992, DB-LINK collects, organizes, and disseminates information related to children and youth (birth through 21 years) who are deaf-blind.

DB-LINK is a consortium-based project comprised of:

- American Association of the Deaf-Blind (AADB)
- American Foundation for the Blind (AFB)
- Helen Keller National Center (HKNC)
- Perkins School for the Blind (Perkins)
- Teaching Research (TR).

DB-LINK will have a regular column in Deaf-Blind Perspectives. DB-LINK staff will write on topics both specific and tangential to DB-LINK. The objective being to provide information useful to the readership of Deaf-Blind Perspectives. This article focuses on how DB-LINK works; what parents, professionals, and other interested consumers can expect from DB-LINK; and how DB-LINK can be accessed.

How DB-LINK Works

Figure 1 depicts how information flows within the project. DB-LINK is founded on the information needs of many different consumer groups. Note that information flows both ways—information is collected from multiple sources and shared with a wide variety of consumers. One of DB-LINK's major responsibilities is to provide information through an inquiry-response process. Consumers with questions call DB-LINK toll-free and talk with an Information Specialist. The Information Specialist determines the nature of the question and those that can be answered immediately will be responded to at once. For most

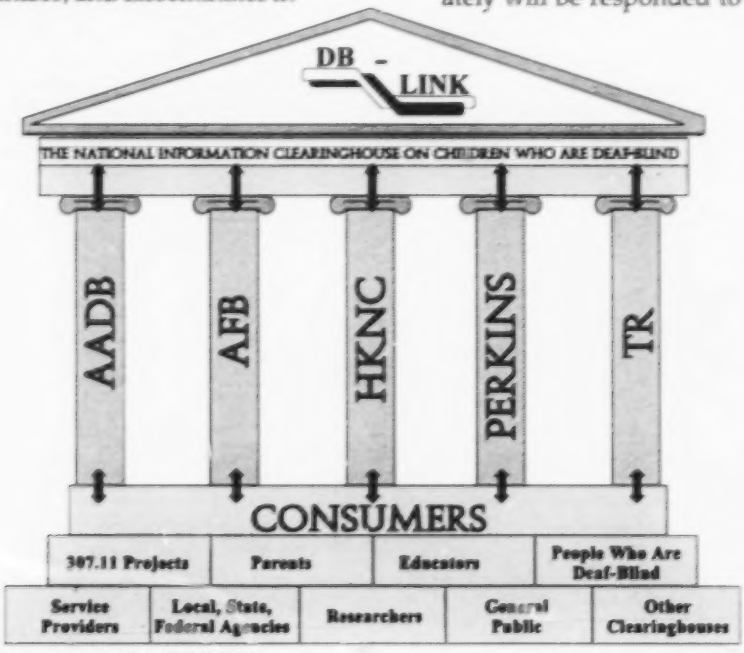

Figure 1 How information moves within DB-LINK

inquiries though, the Information Specialist will check multiple sources to answer the question. Depending on the nature and complexity of the request, the Information Specialist may consult with other Information Specialists within the DB-LINK consortium. In this way, DB-LINK draws upon the collective expertise of project staff to answer inquiries. For difficult or complex questions, the process of asking a question and getting a response may require up to three or more days, plus the time it takes to get back to the inquirer (e.g., mail, phone). At present, there is no charge for DB-LINK's service.

DB-LINK maintains three databases; Catalog, Resource, and Tracking. Bibliographic information on text sources is contained in the Catalog Database; the Resource Database holds information on services; and the Tracking Database allows DB-LINK to monitor information about the requests.

DB-LINK's first two years (1993 and 1994) will focus on cataloging the vast amount of information located around the country. During this developmental period, inquirers will receive responses that are as complete as possible via the developing databases. However, time will be required for DB-LINK to acquire and organize all available information.

What to Expect from DB-LINK

Though DB-LINK has information about specific materials and resources, DB-LINK does not necessarily own these items. That is, DB-LINK does not act as a library or a supplier. Fact sheets (written summaries on topical areas) will be developed on selected topics throughout the project and these will be available as developed for dissemination. Samples of the types of information DB-LINK can provide are listed below.

Responses to questions regarding:

- early intervention
- general education
- health
- recreational services
- employment
- syndromes
- technology
- inclusion
- orientation and mobility
- special education
- medical issues
- social services
- legal issues
- independent living
- transition
- IFSPs, IEPs, ITPs
- communication
- postsecondary education

Referrals to other organizations such as:

- departments of education
- local disability organizations
- research projects
- regional disability organizations
- advocacy groups
- colleges and universities
- professional consultants
- parent groups
- medical centers

Fact sheets (*beginning in year 2*)

How to Access DB-LINK

Office hours are from 9 A.M. to 5 P.M. Eastern time; after-hours callers will be asked to leave a voice mail message, and an Information Specialist will return their call. Consumers can call DB-LINK toll-free:

800 438-9376 Voice
800 854-7013 TTY

Business callers should contact:
Dr. John Reiman
Director
DB-LINK
345 N. Monmouth Ave.
Monmouth, OR 97361

(503) 838-8776
(503) 838-8150 fax.
800-854-7013 TTY

Additionally, DB-LINK can be contacted through:

SpecialNet: TRD
or
INTERNET: leslieg@fsa.wosc.osshe.edu

DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind) is funded through Cooperative Agreement No. HO25U20001 by the U.S. Department of Education, OSERS, Special Education Programs. The opinions and policies expressed by DB-LINK do not necessarily reflect those of the U.S. Department of Education.

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Traces

Regional News

In each issue of Deaf-Blind Perspectives the TRACES project will examine technical assistance topics. This first issue highlights selected recent technical assistance activities from around the country. Readers interested in more information about these activities are encouraged to contact the person listed or the TRACES Regional Coordinator for that area. Other technical assistance activities, as well as topical reviews, will be featured in subsequent issues.

IDAHO, NEW MEXICO, NEVADA, MONTANA, and WYOMING

Systematic identification of children who are deaf-blind is a primary responsibility of the Section 307.11 Projects. To fulfill this responsibility, an understanding of functional screening processes and the ability to review and interpret the results of a student's audiological and visual assessments are necessary.

Multi-state training provided recently to coordinators of Section 307.11 deaf-blind projects from Nevada, Idaho, New Mexico, Wyoming, and Montana provided the first level of training and information in these areas.

The three days of instruction and practical training resulted in:

1. A basic understanding of the issues related to people who are deaf-blind.
2. The ability to review audiological and visual assessment results and interpret their educational impact on a student.
3. The ability to gain functional information regarding students via observation and interview strategies.
4. The ability to recognize that additional assessment information must be collected on particular students for the purpose of determining sensory loss and the educational strategies.

For more information, contact:
Rich Mulholland, TRACES Western Region (503) 838-8773 or
Earlene Dykes, Arizona State Schools for the Deaf and the Blind, (602) 770-3677.

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KENTUCKY

The Deaf-Blind Intervention Program in Kentucky is offering training for parents of young deaf-blind children (ages birth to 3 years) to assist them in the transition from infant/toddler to preschool programs. This two-day training, which is called "Reach for the Stars...Planning for the Future," is a modification of the Personal Futures Planning process used with adolescents and young adults.

Families are encouraged to dream about what they want their child's preschool program to look like. Questions asked include: Will my child go to preschool with children without disabilities? What supports will my child require in preschool? What is the difference between an IFSP and IEP? What rights do I have when my child enters public school? What does a "quality" preschool program look like? Information that a family wants service providers to know about their child is collected in a colorful, illustrated, individual binder which can be taken to the initial IEP meeting.

The training is being offered in all areas of Kentucky where there are young children on the Deaf-Blind census. Anecdotal data indicates that use of this process with this age group has educated families about what services can and should be available as well as having empowered them to request these services for their children. It is hoped that this will enable deaf-blind children in Kentucky to receive appropriate services at an earlier age, and subsequently to better reach their potential.

For more information, contact:
Jennifer Leatherby, Project Coordinator
(606) 257-7909.

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LOUISIANA

To provide a single source of information for families, a statewide family resource network called Families Helping Families has been developed. Its mission statement is: "to enable and empower families of individuals with special needs through a coordinated network of resources, support, and information exchange". Based on an initiative developed by the Louisiana Community and Family Support Act; a coalition was formed of existing family programs, a RFP was issued by the Developmental Disabilities Planning Council, grants were awarded, and Families Helping Families Centers were formed around the state.

Current activities include: infant and toddler family outreach, information and advocacy concerning education issues, inclusive education outreach, and serving as an entry point for the community and family support system. Projected future activities are: coordinate existing efforts, market the role of the resource centers, develop collaborative relationships at the local level, and secure ongoing funding.

The Louisiana Section 307.11 Project is using this network to disseminate information about children who are deaf-blind, to assist in its child find efforts, and to distribute a brochure about the project to solicit requests for technical assistance. It is hoped that these "family friendly" resource centers can assist in providing needed support so that appropriate services can be secured with a minimum of effort and frustration.

For more information, contact:
Joyce Russo, Project Director, (504) 342-1525.

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MARYLAND

The Maryland Deaf-Blind project recently held its' annual Parent Retreat at a nature retreat outside of Bethesda, Maryland. Rooms for families were located within cabins, which allowed contact time between families outside of the planned meeting times. Some information sessions were held outside, giving an open relaxed feel that led to extended discussions. All the children participated in a "campfire", which lead to siblings discussing what being a part of a family with a child who is disabled was about.

It is important to remember that parents and siblings often bring their own wants, needs and concerns. Coordinators must stay flexible enough to allow for such needs to be met while providing valuable information to all participants. It was through this flexibility that the Maryland Parent Retreat was such a success!

For more information contact:
Ms. Loretta McGraw, Project Director (301) 333-2498 or
Ms. Diane Kelly, Project Coordinator, Dr. Julie Jones, Project Coordinator, (301) 405-7915

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NEW JERSEY

The New Jersey Technical Assistant Project identified as the overall project objective, "to provide a solid project infra-structure that will effectively and efficiently meet the informational, training and technical assistance needs of infants, children, and youth with multiple sensory impairments." A three phase process to address seven outcomes of this objective was developed: (a) Conduct a spring retreat, (b) develop support activities for implementation of recommendations, and (c) conduct a follow-up retreat.

Seven project personnel attended a two day retreat in Philadelphia. There, team members discussed the operations and management plan of the project. Consultants Ms. Gigi DeVault and Ms. Mary Fischer, from the University of Washington in Seattle, facilitated the discussions. Creative Problem-Solving (CPS) strategies were introduced for problem solving and decision making processes. Participants were grouped and provided particular discussion topics by the consultants to facilitate the use of the CPS Model.

After the retreat a comprehensive Consultation Services Summary Report was submitted. This report also included Stream Analysis—a technique for diagnosing, planning, and tracking organizational change. Abstract concepts are operationalized using a graphic mapping process as a system of tracking organizational change. Core team members will participate in continued facilitated training on CPS and Stream Analysis in a retreat planned to occur in September, 1993.

For more information contact:
Jerry Petroff, Director of NJ.TAP,
(609) 292-4462.

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WASHINGTON

The Statewide Project for Infants and Toddlers with Hearing and/or Vision Disabilities is a newly proposed project in the state of Washington.

During the 1992-93 period, TRACES provided technical assistance to a statewide task force developed by the Interim Statewide Project for Infants and Toddlers with Hearing and/or Vision Disabilities. Results of this year-long project demonstrated that the following conditions exist for infants and children who are deaf-blind:

1. Approximately 450 children were identified; far below the projected incidence rate for Washington of nearly 1500.
2. Services are fragmented across the state, with families in metropolitan areas far more likely to receive appropriate services than those in rural areas.
3. There is no single point of contact or entry into the system through which families can gain services.

The proposed project's goals generated from recommendations made by the task force are:

1. To improve early identification of infants with sensory disabilities.
2. To ensure statewide educational services and support to families with children aged three and younger with sensory disabilities and the professionals who work with them.

For more information, contact:
Marcia Fankhauser, Project Director, Washington State Services for Children with Deaf-Blindness, (206) 439-6937.

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WEST VIRGINIA

The geography of West Virginia often makes finding and identifying children who are deaf-blind difficult. Separated by mountains, small, rural, mining or farming towns are difficult to reach by car, and may have limited resources in health care and education. Dr. Michael Valentine, Section 307.11 Director for West Virginia, is implementing new steps to reach these rural families with children who are deaf-blind.

Dr. Valentine is putting together a video that describes students who are deaf-blind and where to get more information. This video will encompass all levels of the disability, from high functioning students with hearing and vision losses to students who are multiply disabled, and cover all age ranges from preschool to high school.

This video is planned for distribution to local educational agencies, pediatricians, Ear, Nose and Throat Specialists, and local health clinics. It is believed that these places serve as a meeting place for communities, and have the equipment available to show this information. By viewing this tape parents with questions will hopefully ask those questions of available physicians and educators or directly contact the State Office of Special Education.

For more information contact:

Dr. Michael Valentine, Project Director
(304) 558-2696

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TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO2500001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.

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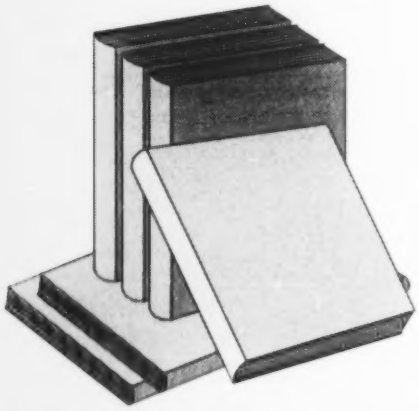

Out of The Shadows
by Robert and Charlene Petty

Out of the Shadows is about the authors' experiences in raising their son Don, who is deaf-blind. The book also contains poems and personal insights written by Don, a 1980 graduate of the University of Oklahoma.

149 pages, cost: $7.95.

To order, contact:
Delano Press
P.O. Box 300223
Midwest City, OK 73140
(405) 447-1170
ISBN 0-9632731-0-8

Independence Without Sight or Sound: Suggestions for Practitioners Working with Deaf-Blind Adults
by Donna Sauerburger (1993)

Sauerburger began 20 years ago as an orientation and mobility instructor for adults who are deaf-blind. Her book explores a number of topics including communication, orientation and mobility, and self determination.

194 pages, cost: $35.00 (specify print or braille).

To order, contact:
American Foundation for the Blind
15 West 16th St.
New York, NY 10011

Technological Resources for Students with Deaf-Blindness and Severe Disabilities
by Nancy Sall, M.S. and Harvey Mar, Ph.D. (1992)

This manual contains a detailed review of 20 computer software programs with vignettes describing how each program was adapted for a particular student; listings of adaptive devices, references, hardware and software companies; and annotated bibliography of 40 articles and papers on special technology

97 pages, cost: $ 6.00 (for duplication and postage).

To order, contact:
Center for Adaptive Technology
15 W. 65th St.
New York, NY 10023
(212) 873-1409 fax: (212) 875-0733

A Resource Manual for Understanding and Interacting with Infants, Toddlers, and Preschool Age Children with Deaf-Blindness
Linda Alsop, M. Ed., Editor (1993)

This manual provides insights, information, and intervention strategies to those who work with infants, toddlers, and preschool age children who are deaf-blind.

The manual is divided into thirteen sections dealing with intervention, communication, auditory development, tactile stimulation, self-help skills, massage techniques, fine and gross motor skills, orientation and mobility, social and emotional development, health care, and play.

576 pages, cost: $50.00

To order, contact:
Home Oriented Program Essentials dba Hope Inc.
809 North 800 East
Logan, UT 84321
(801) 752-9533

A Model Service Delivery System for Persons who are Deaf-Blind
Douglas Watson, Ph.D. and Myra Taff-Watson, M.A., Editors (1993)

This monograph offers a comprehensive presentation of guidelines for a community based approach to planning and implementing delivery of services to persons who are deaf-blind.

Updated from the 1983 edition and includes an overview and description of new population characteristics and demographics, communication methods, interagency planning considerations, and transition.

118 pages, cost: $15.00

To order, contact:
University of Arkansas
Rehabilitation Research & Training Center for Persons who are Deaf or Hard of Hearing
4601 West Markham Street
Little Rock, AR 72205
(501) 686-9691
fax: (501) 624-3515

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Calendar of Events

September 1993

18-19 A Transition Weekend for Parents of Children with Visual impairments and Multiple Disabilities, Howard Johnson's Plaza North Hotel, Austin Texas. Guest speakers: Jeff Strully, Shawntell Strully, Cheryl Powledge, and Natalie Green. Sponsor: Texas School for the Blind and Visually Impaired. *Contact:*
(512) 454-8631 ext. 103 or 156

October 1993

27-29 1993 Project Directors Meeting for the Severe Disabilities Branch, OSEP. Ritz Carlton Hotel, McLean, VA. *Contact*: Connie Jennings
(503) 838-8770

November 1993

4-6 TASH Conference, Chicago Hilton and Towers, Chicago, IL. Keynote speakers: Eldridge Cleaver, Jonathon Kozol. *Contact*: TASH,
11201 Greenwood Ave. N.
Seattle, WA 98133
(206) 361-8870
fax: (206) 361-9208.

5-7 "The Challenge Continues" is the theme for a series of workshops in Seattle, Washington. Sponsored by the National Association for Parents of the Visually Impaired. Keynote speakers: Nancy Ford and Steve Perreault. *Contact:* NAPVI 800-562-6265.

6-7 "Strategies for Inclusion," Portland, Oregon, Marriott Hotel. Keynote: John Champlin, Ann Lynch, Floyd Hudson, Jeff Champagne. *Contact*: Inez Ambrosek, or Nancy Anderson, (503) 378-3598.

December 1993

11-15 International Early Childhood Conference on Children with Special Needs, San Diego Marriott Hotel and Marina, San Diego, CA. *Contact*:
DEC Conference (410) 269-6801

July 1995

16-20 The 18th International Congress on Education of the Deaf, Jerusalem, Israel. *Contact:* Secretariat, 18th International Congress on Education of the Deaf/1995, P.O. Box 50006, Tel Aviv 61500, Israel.

If you have an event you would like to have considered for our next calendar, let us know.

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- ❑ Service provider (*e.g.*, social worker, group home)
- ❑ Technical assistance provider
- ❑ Higher educator teacher/researcher
- ❑ Regular educator (non Spec.-Ed.)
- ❑ Therapist (*e.g.*, OT/PT/speech)
- ❑ Teacher trainer
- ❑ Government personnel
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Deaf-Blind Perspectives

Volume 1, Issue 2 Winter 1993

Blue Chair Time

Joyce Ford
Parent

In 1978 my husband and I purchased our first home along with a few new furnishings for it. Our living room would be graced with what I thought to be the two most beautiful and comfortable blue velvet swivel rockers I had ever laid eyes upon—a statement contrary to the rust, gold, and brown era of the 70s. They spoke a message of unpretentious elegance. It was my finest decorating moment.

Two years later, I rocked my newborn daughter in those chairs. We began to see their presence in the family photo albums as a backdrop to every major celebration we held as a young family. These were the chairs that held grandparents and close friends alike. They were special chairs. They were the kind of chairs you chase pets away from and forbid any kind of food near—the kind of chairs one naturally protects from anything that may jeopardize their preservation. They were the kind of chairs that drew people together.

Enter Riley, 1983. Here was my child who waited so long to come home from the NICU—an infant who fought a war to survive. Here was a child whose right to intimate bonding had been stolen by months of hospitalization. I was an invader to his world, just like all of the other humans who had touched him before. As his mother, my job was to try to erase all of the pain that he had known since birth.

Riley knew nothing about fine upholstery fabric. He knew nothing about unpretentious elegance. My blue chairs soon learned about projectile vomiting, inefficient diapers, and excess wear on the rocking mechanism. Preservation had become a low priority in our household. Survival had quickly taken the lead. I think we were destined to stage that physical and emotional survival in the comfort of the blue chairs. It was the only place that felt right. I called it Blue Chair Time.

Early intervention plans mentioned nothing about Blue Chair Time. They talked about "Quality Intervention Treatment" which I found difficult to put my best effort into. Neither Riley nor I were ready for that. We needed time for us. I needed time to grieve all that had been taken away. I didn't want to answer any more questions. I just wanted some time to hold my baby and cry privately.

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The blue chairs learned that men also cry. They held us in our sadness for several years as we heard the diagnoses—blind, cerebral palsy, deaf—and comforted us with their familiarity in our times of making difficult decisions. All the while we held our children close and, for brief moments, we were able to rock the pain away.

I'm not sure how or when it happened, but gradually the painful moments subsided and the painless ones became more frequent. It became pleasant to sit and hold my son— to dream of possibilities and a future. It was an important time we shared each day and a time we both looked forward to, though perhaps for different reasons. We could just be us in the warmth of the blue chairs. Our best times were often the quiet minutes before the school bus arrived and our paths parted for the day. It was my way of saying, "You are important to me."

Attention

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Volume 1, Issue 2
Winter 1993

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So many things have occurred here on the soft fabric of my chairs—heel cord stretches, oral stimulation, turn taking, and sign language. I've sung endless repetitions of "Row, Row, Row Your Boat" to Riley here. We've counted rings on fingers. We've been through struggles and successes here, from self-contained classrooms to inclusive ones. We've shared our tears and laughter in the chairs that now squeak when they rock and dip down in all the wrong places. The velvet is creased and marred from the business of living.

Riley and I are becoming awkward in the chairs now as we have both increased in size over the years. We don't quite fit the way we used to, yet both of us struggle to hold onto that special place and time, both of us knowing that very soon Blue Chair Time will only exist as a memory.

And when that times comes, I will remember it with all of the wisdom that Riley has brought to me in this past decade. For as much as I believed that he needed it, Riley I think, knew that I needed it as well. I will remember Blue Chair Time as Riley's way of saying, "You are important to me, too."

Funding Alert

Bud Federicks
Research Professor, Teaching Research

The reauthorization of funds for programs for those who are deaf-blind is being discussed as we go to press. Because of the restructuring of educational services, the reform of government planned by the Clinton Administration, and the perceptions of some in the Office of Special Education and Rehabilitation (OSERS) that programs for children who are deaf-blind need no longer be categorically funded, the future of such programs, as we know them, is in jeopardy. Specifically, federal funds may no longer be targeted for programs serving children who are deaf-blind. State-funding for coordinators of state and multi-state projects under Section 307.11 may become obsolete. Specific dollars for research with this population may be melded into the overall educational research budget.

Perhaps this paints a bleak picture and one that may not come to pass. But there are many in various parts of the government who believe that funding for these programs is no longer necessary or desirable. If categorical funding for children and youth who are deaf-blind is eliminated, anyone seeking federal funds for programs for these people will have to compete in programs for those who have other disabilities. When that occurs, programs for low-incidence populations such as people who are deaf-blind, severely disabled, and seriously emotionally disturbed will probably lose much of the funding that they currently have. That funding will move towards larger populations and perhaps into regular education, or it might be transferred to the states in block grants. Most states have very poor records of serving low-incidence populations.

If there is little outside support for children who are deaf-blind, we can imagine that the quality of their services will revert to that prior to the passage of Public Law 94-142. Certainly there will be some school districts who will provide educational programs that are suitable for some children. Certainly some parents will be able to obtain for their children the services they need. But certainly most children who are deaf-blind will not receive the education and support that they need without a 307.11 grantee in each state.

Those who advocate for children and youth who are deaf-blind should write to their senators and representatives to request that not only should allocations to those who are deaf-blind remain as a separate line item in the federal budget, but also that the budget needs to be increased since the number of children identified as deaf-blind has increased significantly over the past five years.

Copies of all letters should go to:

Tom Hehir
U.S. Dept. of Education
MES Building
330 C St. S.W. Room 3090
Washington, DC 20202

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MES Building
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Washington, DC 20202

These letters should cite the need for additional funding. They also need to document the benefits that the current funding has achieved. Stories about specific families are especially poignant.

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Can Inclusive Education Work for Students who are Deaf-Blind?

Lori Goetz
California Research Institute
San Francisco State University

Today's education of students who are deaf-blind faces a tremendous and exciting challenge: How to ensure that students who are deaf-blind, and their families, realize all the benefits of inclusive schooling *and* all the benefits inherent in specialized disability-specific educational practices.

Full inclusion continues to emerge as a promising educational practice. Indeed, in conjunction with widespread school restructuring efforts, inclusive schooling is a practice that may hold the potential for improved educational outcomes for all students (National Association of School Boards, 1993). Full inclusion occurs when students who are disabled are full-time members of age-appropriate, regular classrooms in their own schools, and receive any supports necessary to accomplish participation in both the learning and the social communities of their peers (Neary, Halvorsen, & Smithey, 1992; Sailor, Gee, & Karasoff, 1993). Special education is not a *placement*; it is a *service* that is provided to students in the context of regular classrooms, schools, and communities.

Students who are deaf-blind, however, present unique educational needs to any service delivery system in terms of communication, mobility, and sensory functioning. The heterogeneous nature of these students in terms of cognitive and functional capacities adds complexity to the design and delivery of effective educational programs (Riggio, 1992). While reports of successful participation of students who are deaf-blind in inclusive programs are beginning to emerge (Dennis, Edelman, & Cloninger, 1992), the potential for failure is great. The unique support requirements of these students suggest at least three major areas that fully inclusive programs must address in order to meet the specialized needs of students who are deaf-blind (Collins, 1992).

Curriculum Development

Communication and mobility goals for students who are deaf-blind are appropriate regardless of educational setting or context and must be infused into all educational and social environments. In fully inclusive programs, however, questions emerge concerning the comparative emphasis given to specialized content areas such as experiential learning, functional life skills curriculum, academic participation, and skill acquisition. Further curricular issues include concerns about successful adaptation of both content and teaching methodologies in regular education for learners who do not gather and access ongoing information in traditional ways. How, for example, does an eight-year-old boy who is deaf-blind, has limited mobility and voluntary movement, and uses idiosyncratic means of communication participate meaningfully in a unit about medieval banquets (Gee, 1993)?

One solution to this problem already exists: the federal government has invested in six years of demonstration, research, and validation activities directed by Dr. Kathleen Gee at San Francisco State University[1] to develop specific curricular practices for students who are deaf-blind who are served in inclusive settings. Contextual curriculum development focuses upon identifying the information within ongoing regular classroom events that will assist a student who is deaf-blind to understand and discriminate the routine. Any needed adaptations are used to bring the routine to the student; these adapted cues signal steps in the routine to the student, and systematic instruction of individual performance objectives then occurs.

Contextual curriculum development, for example, was used in determining appropriate instructional objectives for Sally, a second grader who is deaf-blind and multiply disabled. In response to tactile and movement cues that occur during arrival at the Math Table for math enrichment activities, Sally receives systematic instruction in the activation of a loop tape which requests a peer to, "Come here, please." Peers learned to slow down their movements in order to give Sally an opportunity to physically participate with a partner in passing out work materials during the activities.

Contextual curriculum development is an experimentally validated process that enables students who are deaf-blind to continue to learn individualized objectives in inclusive settings. It provides one example, hopefully among many to be developed by the field (Gee & Goetz, 1993), of how to provide effective, individualized curriculum in inclusion programs.

Specialized Services

Students who are deaf-blind need to have available a variety of specialized services ranging from braille, to sign language, to interpreters trained to serve people who are deaf-blind (Curry, 1989; Petronio, 1988). Inclusive programs must also provide these services, rather

1 *Now at the University of Kansas, Dept. of Special Education, Lawrence, KS.*

than conceptualizing the issue as an either/or choice: either inclusion or appropriate specialized services.

A potential solution to this problem also already exists. Full inclusion requires that the teaming process be a *collaborative* one, in which team members—knowledgeable about students who are deaf-blind—share a common vision and goal of the services that are provided (Bruner, 1991; Rainforth, York, & McDonald, 1992). Transdisciplinary and coordinated service delivery models emphasize role release and joint activities, but differ from collaborative teaming models in terms of several essential elements. Collaborative teaming, for example, requires the creation of a common new vision, while coordinated teaming simply reviews the goals of each member for compatibility. Collaborative models utilize dispersed leadership and mutual control among members, whereas in coordinated team models, authority rests with individual team members. Effective collaborative teams thus rely upon consensus building and problem-solving strategies that utilize the expertise of all team members. Shared commitment to multiple "experts" greatly increases the likelihood that specialized service needs will be effectively met.

"Fully inclusive classrooms... create a meaningful and responsive social community"

Social Inclusion

One hallmark of inclusive schooling is the greatly expanded potential for increased social interactions. While opportunity is clearly necessary, it is not sufficient to achieve the outcome of being a valued member in the social context (Sacks & Wolfe, 1990). Successful supported schooling must also provide strategies for using increased social interaction opportunities to achieve meaningful social relationships, ranging from relationships between peers who are and are not disabled, to experiences in the context of disability-specific culture (Lipton, 1993).

Fully inclusive classrooms provide the potential to create a meaningful and responsive social community, in which friendship and interaction among peers are valued outcomes, equal to mastery of academic or functional life skill curricular content (Strully & Strully, 1989; Villa & Thousand, 1992). A potential problem is one of ensuring that a student who is deaf-blind is a valued and active member of the social community. A number of promising strategies are available to achieve this end. The role of all instructional staff in modeling and facilitating natural, normalized, and respectful interactions between the students who are disabled and all adults and peers is an essential first step in which all staff may receive training. Use of a Circle of Friends strategy (Forest & Lusthaus, 1989), in which a core group of students meets regularly with the focus student to share successes and challenges and to make new commitments to activities that will include and support the focus student, is a further strategy for achieving social inclusion. Establishing successful circles of support may initially require recruitment strategies and a formal meeting time, agenda, and roles for participation, but once established the positive social outcomes for all students have been well-documented.

Summary

Serving students who are deaf-blind in programs that protect their unique service needs, while supporting full membership in the life of the school, is critical. Full-inclusion programs have great potential for failure in the three areas just discussed. The widespread use of specific practices that address these problem areas, such as contextual curriculum development, collaborative teaming, and support circles depends, of course, upon resource allocation and personnel training at multiple levels: federal, state, and local. The database for how to achieve effective outcomes through inclusionary schooling for all students, including those who are deaf-blind, is still emerging. As the practice of inclusion continues to grow, we must be alert to the potential areas of failure. We must work to avert these failures before they become accepted inclusive education practices in our nations schools.

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Assessing the Instructional Environment to Meet the Needs of Learners With Multiple Disabilities Including Students who are Deaf-Blind

Bonnie L. Utley
TRACES Regional Director, Northern Region[1]

Many children and youth who are deaf-blind function in a range of settings where the factors related to lighting and visual contrast may be modified to maximize their use of residual vision. Team decisions regarding such modifications, however, must also include information on needs that may arise from the presence of physical disabilities as well as factors related to audition. For this reason, a check list designed to be completed by two or more team members in collaboration is described, and provides a preliminary framework for decisions regarding environmental adaptations.

Team members who complete this check list should strive to achieve an individualized set of environmental adaptations for each student since no two students are alike in their degree and combination of disabilities. Additionally, team members should recognize that the final outcome of this process is to achieve a *balance* between the adaptations made for a particular student.

Multiple aspects of therapeutic positioning, lighting and contrast, as well as considerations regarding audition, must be coordinated to achieve the best overall environment for instruction.

1 The author recognizes the need to consider residual hearing in individuals who are deaf-blind and the need to assess how hearing can be affected by positioning. This paper, however, does not address those assessment considerations. It specifically focuses on visual assessment.

The appropriate application of information obtained through use of this check list requires thoughtful classroom scheduling to balance the multiple instructional, as well as therapeutic, needs of individual students. For example, it may be recommended that a particular student spend short periods of time in a left sidelying position for good body alignment and relief of discomfort caused by asymmetrical distribution of tone. However, that same student may have only one functional eye which may also be on the left lateral side of the body. Team members who serve this student should design a schedule so that minimal visual demands are put on this student when he or she is positioned in this way.

Finally, please note that the items listed on the check list are to be viewed as *preliminary only*. A more thorough assessment of a particular student's ability to benefit from low vision aids (e.g., magnification), amplification, and adapted positioning equipment should be made by team members according to the knowledge base of their respective disciplines.

Organization of the Check List

Team members who complete this check list should do so from the perspective of the student (i.e., the orientation in space occupied by the student should be assumed by the team members as well). This practice will increase the accuracy of the decisions to be made with regard to the two sections of the check list: (a) therapeutic positioning and (b) lighting and contrast. Each section of the check list is described in more detail below.

Section I The items contained in this section of the check list are designed to assist team members to determine whether key aspects of therapeutic positioning may be used to enhance sensory functioning as well as physical ability and normalization of muscle tone. The first items address overall body positioning in sitting, sidelying, and supported supine. The items as written reflect general, desirable attributes of these positions. Team members should collaborate to determine whether or not all the features of a particular position are appropriate for an individual student.

An additional item in this section relates to the position of peers and adults during interaction. Please note that team members and peers should assume a position for interaction that is on the same plane as the student's face if possible (i.e., all parties should be seated or standing in a way that promotes face-to-face regard). This position facilitates communication between all parties, whether speech or nonspeech modes are used. This position may also reduce the likelihood that a student will adopt a head position that may result in abnormal posture or tone throughout the rest of the body (e.g., a hyperextended head and neck).

The final item in this section is the most difficult to complete as it relates to the plane (i.e., horizontal, vertical, or an angle in between these points) used for presentation of instructional materials. Selection of the most appropriate plane for presentation of instructional materials is particularly difficult for students

Environmental Check List

Name of Student _____ Date_____

SECTION I - THERAPEUTIC POSITIONING

1a. Overall Body Positioning (Sitting)

_____a. Student is upright, or reclined slightly, with hips, knees, and ankles at 90-degree angles, or other angle(s) recommended by a therapist.

_____b. Student's head is neutral and upright, with or without external support.

_____c. Student's arms are supported by the table top or wheelchair tray so the elbows are flexed between 90 and 120 degrees.

1b. Overall Body Positioning (Sidelying)

_____a. Student is supported correctly (i.e., lower shoulder is forward; head is in alignment with the spine; hips, knees and ankles are flexed; pillows are placed between and below bony prominences).

_____b. Student is lying on the side that results in the better eye (if known) being on the upper lateral half of the body. (**Note:** *Consultation with the team is recommended to determine whether sidelying on a particular lateral half of the body may be contraindicated*).

1c. Overall Body Positioning (Supported Supine)

_____a. Student is supported correctly (i.e., head in alignment; chin slightly flexed; shoulders rounded forward slightly; hips, knees, and ankles flexed).

_____b. Student's head is stable with or without external support.

2. Position of Peers, Adults, and Materials

_____a. Depending on the student's head control, materials are placed horizontally, vertically, or somewhere in between those points.

_____b. Peers or adults position themselves at or near the student's eye level during interaction.

SECTION II - LIGHTING

1. Amount and Type of Light (indoors)

_____a. A combination of light sources (i.e., natural light plus incandescent light, etc.) are available.

_____b. The entire work surface is illuminated evenly (dependent upon specific task requirements).

_____c. Supplemental lighting is available (if necessary).

2. Position of Light

_____a. Student is positioned so that all sources of natural light (e.g., windows) are behind him rather than behind the instructional/social/communicative partners.

_____b. Supplemental light source originates from over the student's head so the shade directs the light on only the task materials (if necessary).

OR

_____c. Supplemental light source originates from behind and over the shoulder of the student (e.g., over the left shoulder for those who use the right hand and vice versa).

OR

_____d. Supplemental light source originates from behind and over the shoulder of the student on the lateral half of the head where the most functional eye.

3. Glare

_____a. Work surface is made of (or covered with) nonreflective material.

_____b. Materials are made of nonreflective material (if possible).

_____c. The amount of light emitted in the direction of the eye is limited or eliminated.

4. Contrast

_____a. For tasks that rely on materials that are black or dark in color, the background surface is lighter to enhance contrast. Light colored materials use a dark background surface.

_____b. Select or purchase materials that contrast with the work surface (if possible).

Note: The items listed on the check list are to be viewed as *preliminary only*. A more thorough assessment should be made by team members according to the knowledge base of their respective disciplines.

without good head control A neutral head position (i.e., neither turned, nor flexed, nor hyperextented) is the ideal position for many students. For other students, a position in which the head is turned, flexed, or hyperextended may be more visually functional for the student. For those students for whom a neutral head position is desirable, it is recommended that external support be provided to enable this position to be assumed. This is true for the student who is not yet able to maintain his or her head in a neutral position independently for the length of time needed to complete a particular task. Support may be provided by a collar, straps, or through physical assistance provided by an adult, if necessary. For most students, a fully upright posture for at least some periods of the school day is important. Upright posture in either sitting or standing is the most normalized position for participation within more inclusive school or work settings, as well as community-based training. To prevent complete reliance on external support, however, specific intervention strategies to promote more independent head control should be conducted at times other than those that require optimal use of the student's vision. It is simply too difficult for some students to maintain head erect behavior *and* work on a visual task *and* communicate simultaneously.

"Soft white bulbs diffuse the light...and produce a...lower overall output..."

Selection of the most therapeutic upright position should be followed by selection of the best plane of presentation for instructional materials and the student's communication materials (e.g., a communication board, the area for presentation of manual signs). The use of more atypical positions such as sidelying, supported supine, or prone should be reserved for instructional sessions that have a different, less structured, therapeutic or instructional function (e.g., a period of time spent prone over a wedge to promote postural drainage before lunch; "long" sitting during story time in the library).

Section II This part of the check list is designed to assist team members to evaluate four aspects of lighting.

- Amount and type of light
- Position of light
- Glare
- Contrast

Again, it is important to achieve a balance between these various aspects of lighting to achieve sufficient illumination without glare.

To enhance visual performance in a school, community, or work setting it is generally desirable to have a combination of light sources available including natural light from windows and doors in addition to fluorescent and incandescent sources. The surface of the table, wheelchair tray, desk or other surface should be illuminated evenly unless the student fails to respond visually to objects on that surface, even after enhancement of the contrast. In the latter situation, supplemental lighting on the task materials alone may be necessary to provide additional contrast between the materials and the background surface.

There are two factors to consider during selection of an incandescent light source such as a table lamp or "study" lamp. The lamp should have a weighted base, or be attached to the work surface with a "C" clamp to prevent tipping, and the shade should be double-layered. A double-layered shade permits the outer shade to stay cool, an important factor when the light source is positioned close to a student for prolonged periods of time. The lamp should be fitted with a standard indoor bulb (not a "soft-white" bulb) of 60-75 watts. Soft white bulbs diffuse the light too much and produce a substantially lower overall output of light than do standard bulbs. Sources for study lamps may be found in catalogs of equipment for students with visual disabilities, but many study lamps found in hardware stores may meet the needs of most students without incurring high cost.

A second aspect of lighting is the position or direction of the light source(s). Generally, a student should be positioned with his or her back to natural light sources. This recommendation is particularly important for students who rely on sign language input as their view of a signing partner may be limited to a silhouette under these conditions. The other primary light source for most settings is found in the ceiling. The location of supplemental light sources should be from directly over the task (if necessary to promote higher contrast of the materials against the work surface), or from over the student's shoulder on the lateral side of the body opposite the dominant hand (i.e., from over the left shoulder for a student who is right-handed and vice versa). In the latter situation, the supplemental light source should originate from over the shoulder on the same lateral side as the more functional eye. The overall goal is to achieve a well-lit work surface without shadows.

Another aspect of lighting to be evaluated is glare. Glare can be reduced or eliminated through the use of nonreflective material for work surfaces and materials. The amount of light emitted in the direction of the eyes should also be reduced or eliminated.

The final aspect of the environmental check list consists of an evaluation of contrast factors in the selection and placement of instructional materials. Supplemental lighting may be needed when dark materials are being used. In general, dark materials should be positioned on light work surfaces and vice versa.

Contrast factors should be considered in the selection and purchase of instructional materials. For example, a red or dark blue toothbrush should be purchased for placement on a white sink for use during instruction on toothbrushing rather than a white toothbrush. For those situations when color of materials is not optional, the background color of the work surface may be modified instead.

Summary

The environmental check list described here should be used by two or more team members as a *preliminary* tool to guide them in meeting the therapeutic and sensory needs of students who are multiply disabled. Key features of this check list are twofold. First, team members need to recognize a balance between the relative priority of various environmental modifications. Second, team members should recognize that all learning relies on the reception of a sensory, but not necessarily visual, stimulus. Instructional planning made on an individual basis, with consideration of each student's particular combination of sensory and physical disabilities, constitutes the primary factors in this process.

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DB - LINK

DB-LINK: Concept to Clearinghouse

Gail Leslie
Information Specialist, DB-LINK

October 1993 marked the one-year anniversary of DB-LINK, The National Information Clearinghouse on Children Who are Deaf-Blind. In that year, DB-LINK moved from concept to clearinghouse, complete with an 800 number open to any individual needing information related to children who are deaf-blind.

Clearinghouse imparts the image of a busy hub, a sort of informational Grand Central Station. Phones ring. Papers, books, bits, and bytes arrive, are organized, warehoused, and readied for the next question. From the beginning DB-LINK has had to negotiate new ways of executing the clearinghouse model, because, as a consortium project, DB-LINK is a cooperative effort between five different agencies and organizations:

- American Association of the Deaf-Blind
- American Association for the Blind
- Helen Keller National Center
- Perkins School for the Blind
- Teaching Research

This gives DB-LINK five working addresses instead of one. The challenge has been how to centralize resources and create a viable network that will do the things that clearinghouses do.

To some extent, a network is already in place. Each consortium partner provides a range of services for different segments of the population that is composed of those who are deaf-blind. Each has an extensive network of contacts and resources used in the provision of these services. Each also comes with a particular approach to information. In this field, where the content area is well defined and the service population small, a dispersed and informal approach to information has been the norm. Practitioners and providers have relied on their network of contacts and professional exchange to provide them with information related to current practices, new materials or news of workshops. While this informal network meets the particular needs of those who are in it, it is less than adequate and often inaccessible for those outside of it (i.e., the general public, a parent, a teacher). DB-LINK, which has as its task the coordination and centralization of information, creates a complimentary "formal" network. With the creation of a consolidated repository of resources and materials, DB-LINK ensures a collaborative effort that broadens access, reduces parallel efforts, focuses on needs, and promotes and communicates new developments.

Our first step was to harness the resources of this network. This required building the DB-LINK databases. Using INMAGIC+, a full-text database software program, we designed the Catalog and Resource Databases. Each consortium partner is responsible for the data entry of materials and information at its site.

The Catalog Database is the pathfinder to articles, books, curricula, proceedings, and any other materials related to children who are deaf-blind. Perkins School for the Blind has provided more than 2500 entries from the Samuel P. Hayes Library. American Foundation for the Blind has contributed more than 150 entries from the AFB Deaf-Blind Project. Teaching Research has added more than 200 entries of recent acquisitions. Helen Keller National Center is entering a growing body of articles and books that relate to transition. This database has helped to answer questions such as:

- Is there anything written that outlines what elements should be included in an ITP?
- How do I find out how to fund the technology that the speech therapist says would help my child?
- Are there any new materials on communication that would be useful for parents in our state?
- Is there documentation on the effectiveness of this tactile communication device that would help me to negotiate with my insurance company?

The Resource Database contains names of consultants, programs, services, newsletters, research contacts, and so on. With more than 400 entries, it has provided us with the answers to many questions:

- Are there any conferences or workshops on early intervention coming up?
- Who would know if the state of Florida has a transition plan in place?
- How many persons who are deaf-blind receive service in the state of South Carolina?

- Which state projects produce a newsletter?
- Are there consultants in my state who would do an assessment of a new child in our program?

Technology has provided us with many of the tools crucial to creating one clearinghouse with five partners. Modern telecommunications programming allows us to be bi-coastal with our 800 number. The phone is answered for four hours at Perkins on the east coast and then rolls over to be answered for four hours at Teaching Research on the west coast. Database files and updates are transferred via modem. E-mail allows us to communicate about requests and new occurrences any time of the day.

Technology also allows us to become part of the larger network of information and resources available from both commercial vendors and other federal projects. For example, SPECIALNET has been useful both for promoting ideas and exchanging information via the Deaf-Blind Bulletin Board. The SPECIALNET database ONE SOURCE has been searched in response to some of our requests as well as to update information in our databases. COMPUSERVE allows us to monitor other disability-related bulletin boards as well as access the full text of the National Organization for Rare Disorders (NORD) database. We also make use of the ABLEDATA database as well as many of the databases available on DIALOG.

The INTERNET is an exciting addition to our resources. DB-LINK makes use of the ERIC databases, the Library of Congress Catalog, and the holdings of the National Library of Medicine. "Gophers" available through university and college campuses give us access to MEDLINE and campus libraries across the world. Through E-Mail on the INTERNET, DB-LINK is an active participant in the DEAF-BLIND Forum, an international network of parents, educators, and service providers who communicate and exchange information and ideas related to all aspects of people who are deaf blind.

As DB-LINK moves into its second year, we continue to expand and refine our ideas for building an efficient and effective clearinghouse. Cooperation and exchange remain the important ingredients for creating the informational "links" that will allow us to take an in-depth approach to the questions we receive. We invite your communication and look forward to your contributions.

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1992 National Symposium on Children and Youth Who Are Deaf-Blind

The proceedings from the 1992 National Symposium on Children and Youth Who Are Deaf-Blind is now available from Teaching Research Publications.

This three day symposium, supported by the U.S. Department of Education, identified critical issues, effective practices, and future directions in the provision of educational and related services to children and youth (birth to 21 years) who are deaf-blind.

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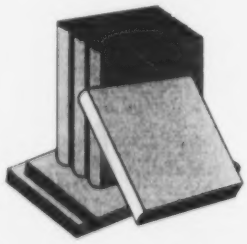

For Your Library

Choosing Options and Accommodations for Children (COACH): A Guide to Planning Inclusive Education

by Michael Giangreco, J. Chigee, Virginia Iverson (1993)

COACH is an assessment and planning tool designed to identify the content of a student's educational program based on individually determined valued life outcomes.

189 pages, cost: $29.00

To order, contact:
Paul H. Brooks Publishing Company
P.O. Box 10624
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(800) 638-3775

Continued on page 15

Traces

Regional Reports

DELAWARE

Effective training that is based on needs of students, families, and staff members who provide services to children who are deaf blind is a primary objective of the Delaware Deaf Blind Project.

Peggy Lashbrook, 307.11 Coordinator, and service providers identified technical assistance needs that focus on development and expansion of functional programs. Peggy Lashbrook, Joan Houghton, consultant, and Cheryl Kennedy, TRACES Project Northeast Regional Coordinator, conducted a series of teleconferences to develop strategies for meeting this need.

Two needs assessment surveys, (i.e., Early Childhood Intervention Survey and a School Age Intervention Survey) were developed by Joan Houghton. Participants were requested to complete the items listed on the survey form by reviewing each item, checking their priority need(s) and the method in which they would like technical assistance to be delivered (e.g., inservice training, on-site consultation, meeting with the consultant individually or in a group with all participants, or being provided with information such as where to obtain resource materials). The results from this survey will be used in combination with information gathered during initial on-site consultation visits to plan the format and content for further follow-up consultation visits. The three team members planned to conduct the consultation when they traveled throughout the state the last week of September. Over a one-week period they expected to visit two full inclusion sites, one special school site, and one nursing home.

This technical assistance activity is especially exciting. Not only will it assist the project coordinator in developing a long-range plan for delivery of technical assistance, but it will also afford the opportunity to meet individual needs of service providers.

For information, contact:
Cheryl Kennedy
Dept. of
Instruction/Learning
5N01 Forbes Quadrangle
University of Pittsburgh
Pittsburgh, PA 15260
(412) 648-7176 Voice/TTD

or
Peggy Lashbrook
Delaware Program for
the Deaf/Blind
620 East Chestnut Hill Rd.
Newark, Delaware 19713
(302) 454-2305

MINNESOTA and IOWA

Personnel from the Minnesota Deaf-Blind Project are in the process of developing a coordinated system to provide assessments of the functional sensory abilities of children and youth who are deaf-blind. As one step in this process, Minnesota project personnel have developed a collaborative relationship with the 307.11 project personnel from the State of Iowa. In September, Linda DeRosiers and Steve Maurer traveled to Minnesota to introduce and discuss components of the Iowa Team Assessment Model. The recipients of this information, who are now reviewing the content and process described by Ms. DeRosiers and Mr. Maurer, met in October to discuss replicating this assessment model in Minnesota. Ms. DeRosiers and Mr. Maurer revived the plan and gave recommended strategies for its implementation. They will also provide informal, ongoing consultation as the team assessment model is developed and implemented.

For information, contact:
Eric Kloos or Jo Hauskens
Minnesota Deaf-Blind Proj.
201 Capitol View Center
70 West County Rd. B2
Little Canada, MN 55117
(800) 848-4905

or
Steve Maurer
Iowa Dept. of Special Ed.
Grimes State Office Bldg.
Des Moines, IA 50319
(800) 281-3576

GEORGIA

For the past three years, Richmond County, Georgia, has been the site of a model program for the education of children with who are deaf-blind. Systematic instruction by consultants has been provided in different areas of the education of elementary aged children who are deaf-blind. Areas of instruction include communication, challenging behavior, functional activity-based curriculum, and community-based instruction. Teachers who have been involved in the program in previous years have found the instruction effective and have used these skills with the students in their classrooms.

As in many school systems around the country, elementary aged students in the Richmond County Schools who are disabled are now moving from one centralized school to schools within their home communities. In some instances, the teachers who now have children who are deaf-blind in their classrooms are not the teachers who participated in the previous model site program. However, to continue the effective educational practices and programming, a number of strategies have been used. A consultant has visited the new classes to review the use of curriculum and community instruction within the new environments. The students have moved to the new schools with detailed reports, not only their of educational program, but also of communication and behavioral systems. Direct contact between new and previous teachers has also been made

in a systematic manner to answer any additional questions. These strategies have made the transition to new school settings more effective for both the students and teachers.

For information, contact:
Toni Waylor Bowan
Dept. of Special Education
Georgia State University
Atlanta, GA 30303
(404) 651-4089

PUERTO RICO

Providing effective services to preschool aged children who are deaf-blind is one of the primary goals of the Deaf-Blind Project in Puerto Rico. To reach this goal, the Project has employed the assistance of a local Head Start program. This Head Start program, with space provided in the school where the Deaf-Blind Project is housed, is an inclusive environment where children are and are not disabled learn, play and work together.

Enrolled in the Head Start program are children who are hearing impaired, children of the school staff, children from the local community, and children who are deaf-blind. Bringing these 15 children together in a main classroom has been accomplished with few changes in the usual operating procedures of the Head Start program. Through teaming of the teachers and paraprofessionals originally employed by each program, modifications and adaptations for children within the Head Start curriculum are made as needed; new activities incorporating all students are developed; and challenging situations that may arise in the classroom are discussed and proposed solutions are implemented. Through this collaborative effort, the preschool children in this Head Start program are successfully meeting the fascinating challenges that face them.

For information, contact:
Thomas Santana
Antiquo Hospital Ruiz Soler
Edificio B
Bayamon, PR 00923
(809) 782-8994.

WESTERN REGION BROCHURES

Providing awareness level information regarding children who are deaf-blind should be inherent to all 307.11 deaf-blind projects. One method widely used is dissemination of literature describing the project and common behaviors of children who are deaf-blind. For many states, the cost of producing such literature is prohibitive. Through collaboration, the fourteen states in the western region of the TRACES Project have developed an awareness level brochure for use by all states in the region.

The collaborative process was three-fold. First, a resource comprised of generic information that defines deaf-blindness and highlights common behaviors and available services was developed by a small working group. Next, the document was reviewed by an outside expert and the 307.11 coordinators within the western region. Finally, the document was individualized for each state by including the project title, contact person, address and phone number on the back panel of the brochure.

Each state in the western region has shared in the planning, development, and cost of the brochure; however, the singularity of each state's deaf-blind project is retained through dissemination of an individualized product.

Future plans for the brochure include a Spanish translation for the large Spanish speaking populations in the western region.

For information, contact:
Paddi Henderson
Teaching Research
345 N. Monmouth Ave.
Monmouth, OR 97361
(503) 838-8778

UTAH

Access to comprehensive and integrated services is critical to optimum educational opportunities for children who are deaf-blind. Often, families and educators become confused, frustrated, and feel abandoned as they try to access existing services, or create new services. The Utah State Office of Education and the Utah Project for Children with Dual Sensory Impairments recognized this problem and have engaged in a strategic planning process to coordinate and integrate all services within the state educational system. These two agencies invited representatives from all agencies within the state that could serve children who are deaf-blind to participate in the development of a statewide strategic plan. The most important outcome of this process, from the consumer's position, has been the establishment of a single point of contact for accessing all services.

By calling the single point of contact, technical assistance services and resources regarding families, schools, transition, supported employment, and statewide networking may be accessed by families of children who are deaf-blind and educational programs serving these children.

For information, contact:
Blaine Seamons
Utah Project for Children with Dual Sensory Impairments
846 20th St.
Ogden, UT 84401
(801) 629 - 4896

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TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.

Looking at Self-Stimulation in the Pursuit of Leisure

Or I'm Okay, You Have a Mannerism

Kate Moss, TSBVI Outreach Family Training Coordinator

Deaf-Blind Perspectives Editor's Note: The following is reprinted with permission from Vol. V, No. 3 of P.S. NEWS!!!

P.S. NEWS!!! Editor's Note: I would like to thank, Jim Durkel, Craig Axelrod, Gigi Brown, David Wiley and Stacy Shafer for taking their time to discuss the topics of leisure and self-stimulation with me. I would also like to thank Gretchen Stone, Ann Silverrain, Barbara Bellemo-Edusei, and Robbi Blaha for their help.

Leisure time, the time free from work or duties, is important to all human beings. It is the time for doing something that will relax us or energize us so that we can renew ourselves to face the demands of our lives. It is something we require as much as food or sleep to stay healthy and sane.

We all have different ways of spending our leisure time. What might be a leisure activity for me (reading a mystery) might not be leisure to you. We know and accept this about each other. When considering leisure skills for children who are deaf-blind, however, we often focus on activities that do not relax or positively energize them. We spend their time getting them to participate in "play work" as one young man who is deaf-blind terms it. Learning to play games, participate in arts and sports activities, or other pursuits as a part of their educational programming may be beneficial for children in many ways, but these activities don't necessarily meet their needs for leisure.

The type of activities that often do provide relaxation or amusement for these individuals includes behaviors that most of us find unacceptable: flicking your hand in front of your eyes, pulling threads out of your clothes, making repetitive sounds, and so on. These behaviors are considered self-stimulation. As such they are often perceived negatively because they do not look normal, may interfere with learning, and can often become self-injurious. Yet these behaviors serve a positive purpose for these individuals as well.

Changing our perception of these self-stimulation behaviors may be the most reasonable course to take in addressing this issue. Especially if this change of perception also helps us find ways to give more information to the child who is deaf-blind and consequently reduce his need to find stimulation on his own. These behaviors may also hold the key to information about his or her personal preferences, which we may tap into to select more appropriate choices for typical leisure options.

Stimulating Experiences

Most of our leisure activities are nothing more than self-stimulation behaviors that have become highly ritualized over time and made socially acceptable. There is nothing intrinsically valuable or reasonable about leisure pursuits such as bungee jumping, playing cards, dancing, playing video games, listening to music, or smoking.

People participate in these different activities because they find them to be pleasurable and because they alter their physical state. Each of these activities provide us with a particular type of sensory input (see Table 1). There is not necessarily a great difference in so-called self-stimulation behaviors and some of these activities beyond the fact that some are more socially acceptable and normal in appearance than others. For example, what is really so different about banging a table and banging a drum, rocking to silence and rocking to music, making repetitive sounds and imitating bird calls, spinning for no apparent reason and spinning in a ride at the amusement park?

Table 1

Sensory Channels	Miss Manners Guide to Appropriate Self-Stimulation	Creative Variation Which May Plug You Into a Written Behavior Plan
Tactile: Information received by touch (throughout body surface) includes sensitivity to light touch, pressure, pain, and temperature.	Twirling hair, drumming fingers, playing with condensation on a drinking glass, fingering fabrics, rubbing eyes, pulling on beard	Pulling hair, lying in front of the air vent, slapping face/ear, playing with spit, rubbing head
Proprioceptive: Information about the relative positions of parts of the body. This information comes through sensations arising in the muscles, joints, ligaments, and receptors associated with the bones.	Snuggling in quilts, cracking knuckles, jiggling/crossing legs, sitting on your leg	Burrowing into furniture, wrapping arms inside tee-shirts, wrist flapping
Visual: Information received through the eyes/seeing.	Gazing at your fingernails, hands and rings, watching television without the sound, window shopping, flipping through magazines, eye pressing	Flicking hand in front of eyes, flipping pages of books, light gazing, playing with transparent or shiny objects, eye poking
Auditory: Information received through the ear/hearing.	Humming/whistling, tapping a pencil on a surface, playing background music	Vocalizing or making sounds, banging on objects, tapping objects together next to ear

Sensory Channels	Miss Manners Guide to Appropriate Self-Stimulation	Creative Variation Which May Plug You Into a Written Behavior Plan
Olfactory: Information received through the nose/smelling.	Wearing perfume, sniffing magic markers, scratch and sniff stickers, burning incense	Rubbing feces on the body and smelling, smelling other peoples' hands or shoes
Gustatory: Information received through the tongue/lips, tasting. Closely tied to the sense of smell.	Chewing flavored toothpicks, sucking on mints/hard candy, smoking, sucking on pens/jewelry	Mouthing objects, chewing on hair, sucking on fingers, licking objects
Vestibular: Information received through receptors in the inner ear that enables us to detect motion, especially acceleration and deceleration. Closely tied to the visual system which provides information to the vestibule located in the inner ear.	Rocking in chairs or rocking body, amusement park rides, dancing, twisting on bar stools, skating, sliding	Rocking body, spinning, twirling in swings, head rocking
Our brain seeks out stimulation through the channels of our senses. Each of us seek out this stimulation in a variety of ways. Society accepts some of these behaviors without question, yet feels very differently about others. This acceptance seems to be arbitrary in some cases. This chart shows examples of how individuals typically fulfill this craving for stimulation and how some self-stimulation behaviors of children who are deaf-blind parallel these behaviors.		

Each day a good portion of our energies is spent in self-stimulation. Look at the people around you. You are in a room with your family watching television or at a meeting with a group of co-workers. Although you are seemingly engaged in the same activity, your daughter or colleague is playing with her hair. Your son or your office mate is shaking his leg and tapping out rhythms on the arm of the chair. Your husband is flipping channels with the remote or your boss is flipping papers. If you ask them what they were doing, they would reply that they are watching television or having an important meeting. They would be less likely to say they were channel surfing, twirling their hair, practicing the drum part for "Wipe Out," or fanning their papers.

Each of us, even those of us with more intact central nervous systems, also tolerate differing degrees of stimulation. Look at the difference in the preferred musical tastes (and intensity levels) between the teenager and the 40-year-old. Although most teenagers enjoy a megawatt rock concert with all the trimmings, most adults are more inclined to seek out softer music or silence in a dimly lit room. In the same way, children who are deaf-blind vary in the amount and intensity of stimulation they need.

If we come to accept that self-stimulation is an important and valid activity for individuals who are not disabled, then we must begin to revise our thinking about addressing self-stimulation behaviors in individuals who are deaf-blind.

Can this behavior be stopped?

In looking for the answer to this question, first take a look at yourself. Try this little exercise: Identify one of your own deeply cherished self-stimulation behaviors such as cracking your knuckles, humming, or sliding a charm on your necklace. Try to keep track of how many times during the course of a 24-hour period you engage in this behavior. Then spend the next 24 hours refraining from this behavior. If you succeed, then try to extinguish that particular behavior for a year. Stop this behavior under all kinds of circumstances such as times of stress or times of idleness. Can this behavior be stopped? Answer the question for yourself.

Children who are deaf-blind participate in self-stimulation behavior to calm, to energize, or to get feedback just as you or I do. Most of the time you can't completely extinguish the behavior, nor should you because it does serve a purpose.

Can this behavior be redirected?

Most parents find that their child is more likely to participate in self-stimulation behaviors when he or she is idle or stressed. Interacting with your child in some way may break up the self-stimulation. If the behavior appears in response to stress, finding ways to help him relax (e.g., massage, being wrapped up in a quilt, etc.) may reduce the amount of time spent in this behavior that you find inappropriate or harmful. However, if your child is left alone, it is likely he or she will re-engage in this activity as soon as the opportunity presents itself.

Can this behavior be contained by allowing it in certain locations or at certain times?

Some behaviors may present problems because they are considered socially inappropriate. Those of us who are smokers have learned to refrain from our favorite self-stimulation behavior on airline flights, but we all know exactly where to go in the airport to have that last cigarette before the flight leaves.

With some effort many children can learn to remove themselves to their bedroom or a private place when engaging in self-stimulation that is considered socially unacceptable. Using calendar symbols to represent this favored activity and scheduling the activity as part of the child's day may help the child refrain from this particular self-stimulation behavior for increasingly

longer periods of time. He or she may stay involved in other kinds of activities.

Can this behavior be modified or expanded into more socially acceptable self-stimulation behaviors?

The value of self-stimulation behaviors is what the behavior tells you about how your child takes in information. If your child likes to burrow down inside the cushions of the couch, be held or hugged a lot, enjoys massage, you can assume that he or she is stimulated by information received proprioceptively. If your child likes to vocalize, listen to music, or bang things together, you can assume he or she is stimulated by information received auditorially.

These behaviors can be used as a way to explore the individual's preferred sensory channels for receiving information from the world. With this information we may find preferred sensory experiences around which we can develop more mainstream leisure activities for children—activities that they will also come to view as leisure. For example, if a child enjoys the visual sensation of lights we can find age-appropriate toys that might be motivating to him. In addition to familiar toys such as Lite-Brite, consider lava lamps, continuous wave machines, lighted drafting tables for drawing, and even some Nintendo-type games. You might also consider extra curricular events such as visiting arcades, decorating with lights for appropriate holidays, or lying in a hammock under a tree watching the play of light through the leaves.

"...self-stimulation behaviors...tell you...how your child takes in information."

Take time to observe the types of self-stimulation that your child participates in and when this behavior occurs. Watch him or her and make notes about what you see and when you see it. Then try to see if there is any pattern to these behaviors that would give you insight to the types of stimulation preferred and what purpose it serves. At the same time note what types of activities he or she finds aversive.

When you have a good understanding about preferences, brainstorm ways to offer other stimulation activities or perhaps modify or expand on the preferred self-stimulation. Ask for help from your child's teacher, physical therapist, occupational therapist, and others. Look at children of the same age and try to find toys or activities that may make the self-stimulation behavior appear more normal.

Sometimes your child's favorite self-stimulation activity can be modified or expanded in a way that will make it more socially acceptable. For example, everyone knows the nail-biter, but do you recognize them when they become the manicurist? Several of my friends substitute the more acceptable behavior of nail care for their favorite activity of nail biting. They carry a complete manicure set with them at all times and can often be seen in meetings quietly filing or clipping a nail. They buff, cream, and polish. They examine them for chipping, snags, splits. They are rewarded by others who admire their efforts instead of being held in low esteem as one of those nervous nail-biter types.

You should realize, however, that generally your child will need support from you to seek out these more acceptable behaviors. Their first preference will generally be for the behavior they have developed on their own.

Can the environment be engineered to make this behavior safer if the behavior is detrimental to the child or those nearby?

People who like to jump off things are great examples of engineering the environment to make a dangerous self-stimulation behavior safer. These folks (skateboarders, skydivers, skiers, etc.) have developed elaborate ways of placing themselves in extremely dangerous activities and surviving. We have industries based on protective clothing and equipment that will allow them to hurl themselves through space and make a safe landing.

Frequently, with children who put themselves in danger of bodily harm by participating in self-stimulation activities that may create physical danger to themselves or others, the best you can do is to provide protection. Splints, helmets and other devices sometimes must be used *temporarily* to protect the child and others who are nearby.

In addition to providing protection from the effects of the behavior, it is important to look at the cause of the behavior. Often times these behaviors erupt in response to real physical problems that the child is not capable of communicating. Emergence of these behaviors or increase in these behaviors might indicate pain (e.g., ear infections) or decrease of sensation (e.g., retina detachment). Seeking out appropriate medical examinations when this type of behavior emerges or escalates is very important to the child's health and safety.

Emotional and environmental conditions may also provoke increases in these self-injurious behaviors. One young woman exhibited a dramatic increase in self-stimulation behavior after the death of her father. The amount and intensity of the behavior posed concerns for her safety and the safety of others. Since there was no physiological basis for her behavior, the family spent time with her looking at pictures of her dad, going to the cemetery with her, and trying to participate with her in activities that were associated with her father. After a period of time, the behaviors decreased to levels that were in line with the period before her father's death.

Changes in schedules or moves to new environments can also bring about increases in self-stimulation. Helping the child anticipate these changes and providing as much consistency as possible through routines during times of change are strategies that may prove helpful.

Conclusion

Like you and me, children who are deaf-blind have a need to participate in self-stimulation activities. Because their behaviors appear very different from our own and can interfere with learning, or even become dangerous, they are viewed negatively by many people. Changing our perception about these behaviors may help us to deal with them in a better way.

There are a number of ways to deal with self-stimulation behaviors. Plan ways to keep the child more involved with others during the course of the day. Work to help him or her contain the behavior or engineer the environment to make the behavior safer. Schedule time in the day to allow your child this preferred activity. Look at ways to adapt the behavior so that it will appear more normal. Learn to use the information these behaviors offer about your child's preferred channels of sensory input to develop recreational and social pursuits that may be enjoyable—even if these activities will not entirely meet his or her leisure needs. Finally, accept that you will probably never completely extinguish these behaviors without having them replaced by other self-stimulation behaviors. Self-stimulation is common to all humans and serves an important purpose.

Resources and Additional Reading:

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Kotulak, R. (1993 June 6). Unlocking the Mysteries of the Brain. Austin American Statesman, pp. G1, G4-6.

Restak, R. (1984). The Brain. New York: Bantam Books.

Romanczyk, R. G., Kistner, J. A., & Pluenis. (1982). A. Self-stimulatory and Self-injurious Behavior: Etiology and Treatment, pp. 189-254 in Autism and Severe Psychopathology, Advances in Child Behavioral Analysis and Therapy, Vol. 2. John Steffen & Paul Karoly (Eds.). Lexington: Lexington Books.

Rojahn, J. & Sisson, L. A. (1990). Stereotyped Behavior, pp. 181-223 in Handbook of Behavior Modification with the Mentally Retarded, 2nd Ed. Johnny Matson, (Ed.). New York: Plenum Press.

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Van Dijk, J. (1968). Movement and communication with rubella children. Presentation: Annual General Meeting of the National Association for Deaf/Blind and Rubella Children.

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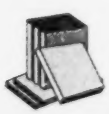

For Your Library

continued from page 9

Innovations for Meeting Special Problems of Children with Deaf-Blindness in the Context of Regular Classroom

by Washington Research Organization (1992).

Ten documents presenting data that demonstrate the level that students were interacting with their peers in school and the effectiveness of collaborative teams.

Number of pages: (varying length), cost: varies from $1.00 to 10.00 ($19.00 for all 10).

To order, contact:
Washington Research Organization
103 Miller Hall DQ-05
College of Education
University of Washington
Seattle, WA 98195
(206) 543-8565

MAPS: A Plan for Including All Children in School

by Services for Children and Youth with Deaf-Blindness Project, Kansas State Board of Education (1991)

The McGill Action Planning System (MAPS) provides guidelines for bringing together family members, friends, educators, the student, and peers, for full inclusion planning of students who are disabled.

19 pages, cost: none

To order, contact:
Services for Children and Youth with Deaf-Blindness Project
Media Division
P.O. Box 189
Girard, KS 66743
(800) 531-3685

Collaborative Teaming for Inclusion-Oriented Schools: An Introduction and Video Guide

by In School and Community Settings Project, Kansas State Board of Education (1991)

A videotape and videoguide describing the concept, purpose and rationale of collaborative teams. The videotape and guide may be borrowed free of charge. The borrower pays for return postage.

To order, contact:
In School and Community Settings Project
Media Division
P.O. Box 189
Girard, KS 66743
(800) 531-3685

Collaborative Teaming for Inclusion-Oriented Schools: A Resource Manual

by In School and Community Settings Project, Kansas State Board of Education (1992)

This resource manual focuses on the development and enhancement of student program planning teams in inclusion-oriented schools.

39 pages, cost: none

To order, contact:
In School and Community Settings Project
Media Division
P.O. Box 189
Girard, KS 66743
(800) 531-3685

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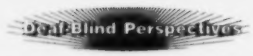

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- ❑ Technical assistance provider
- ❑ Higher education teacher/researcher
- ❑ Regular education (non Spec.-Ed.)
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Deaf-Blind Perspectives

Volume 1, Issue 3 Spring 1994

A Dangerous Misrepresentation of the Facts

In

The 15th Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act

Vic Baldwin
Director, Teaching Research

Every year the Office of Special Education Programs is required to produce an Annual Report to Congress (U.S. Department of Education, 1993) that summarizes the national statistics on the numbers of children who received special education and related services under IDEA (Part B) and Chapter 1 of the Elementary and Secondary Education Act (89–313). In order to generate the information needed for this report, each state director of special education must count and compile specific demographic data on all children his or her state has served within the last year under these two funding authorities. The agreed-upon date at which time this count will officially occur is December 1st of each year.

Each state department of education receives its demographic information from the educational service providers within the state. The demographics mainly consist of age, sex, primary and secondary disability, the type of educational setting, and the exiting status of the older students. Once this information has been received by the state department, it is checked for completeness and eventually forwarded to the U.S. Department of Education where it is compiled into the Annual Report to Congress.

The Annual Report is at least an inch and a half thick and contains over 350 pages. It is full of tables that present the information in hundreds of different ways. For the most part, the tables show the numbers of students across all of the states by age groups, funding authority, educational setting, or type of disability.

The Problem

The reported numbers for the disability category of deaf-blind are *grossly* in error! The first table in the Annual Report (p. 3) shows that the total number of students served in special education programs has been steadily increasing for the past 15 years, with a 2% to 4% jump in each of the last three years. The second table (p. 4) *indicates that there are only 1423 students reported nationally under the disability category of deaf-blindness.* This is in *serious* conflict with the nearly 8500 students that are reported by coordinators of programs for those who are deaf-blind in each of the 50 states and territories. Advancing the problem even further, the Annual Report states on page 9 that the number of children under Part B programs categorized as deaf-blind has decreased by 42% in the last 10 years.

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Discussion

My comments will be directed only at those sections of the Annual Report that deal with the disability category of deaf-blindness. I believe the data presented in the Annual Report are in fact dangerously misrepresentative, and I will attempt to discredit the numbers and suggest alternatives.

The Annual Report does *not* acknowledge that the Secretary of Education is also *mandated* to conduct an annual count of persons who are deaf-blind, from birth to age 21. Since 1986 the U.S. Department of Education, Office of Special Education Programs has contracted with Teaching Research to conduct this census. This is carried out by requiring the coordinators of programs for those who are deaf-blind in each of the 50 states and territories to report the number of persons who are

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deaf-blind whom they have identified. This mandated annual deaf-blind census must coincide with the annual state effort to determine the overall count on December 1st. The deaf-blind census requires considerably more information than the state report and therefore is more complete. At a minimum, the Annual Report should include the data that are generated on the federally mandated deaf-blind census and some narrative to explain why the two reports are so different.

Some of the additional information that is gathered on the deaf-blind census provides details on degree of hearing loss, degree of vision loss, etiology, additional disabilities, the funding authority, educational setting, living arrangements, and finally, the label or category that the state department of education used when it counted the student. This last area has shed a great deal of light on why the state department count for the number of students who are deaf-blind is so low.

Of the approximately 8500 persons identified by program coordinators, nearly 50% have been categorized by state departments as "multidisabled" or "mentally retarded." In many of the other cases, the states prefer to use the categories of "vision impairment" or "hearing impairment" as the primary classification. Placement in one of these categories does not mean the student does not have sufficient disabilities in the areas of hearing and vision that would qualify them as being deaf-blind.

"We can not allow our lawmakers to think that there are only 1400 deaf-blind children nationwide."

Over the years attempts have have been made to resolve the large discrepancy, between the way state departments and program coordinators count children, without accusing either group of wrongdoing. It appears that, for a variety of reasons, state departments do not like to use the "deaf-blind" label. Most states will not deny that these students have losses in both hearing and vision. There is a high probability that these students are in programs for multidisabled students. The teacher is probably certified to teach multidisabled students but such certification does *not* guarantee they have experience or competency with students who are deaf-blind. If a school district uses the label of "deaf-blind," it runs the risk of noncompliance or having the teacher questioned for appropriate credentials. Identifying the student as deaf-blind would clearly suggest that the instruction *must* take into account the loss in *both* hearing and vision. Legally, the safest way for the school district to operate is to use a classification for which it has a qualified teacher.

Each state has a coordinator of programs for those who are deaf-blind who is committed to either full time, or to some significant amount, and this coordinator's job is to locate, assess, and be an advocate for appropriate programming. Therefore, it stands to reason that this person should be the primary source of information about the deaf-blind population in that state. We have advised the coordinators not to get into a confrontation with the state department classification system. In order to justify their classification, which may differ from the state's, they need to supply convincing information about each person's hearing and vision levels and make every effort to document the etiology. The documentation provides a defense for placement of a person on the deaf-blind census. Given all of these precautions and conditions to identify a person as one who is deaf-blind, the likelihood of this count being considerably more accurate than the one from the state department increases significantly.

If none of the arguments so far have convinced you that the data in the 15th Annual Report are in error, then try this: On page 171 (table AA4) there is a breakdown of how many students who are deaf-blind are reported by each state, covering the age ranges from 6 to 21 under both funding authorities (Part B and 89–313). The following is a sample of the numbers of students who are deaf-blind that state departments of education have reported as compared to the deaf-blind Coordinator report.

	15th Annual Report	Program Coordinator Report
Arizona	0	92
Arkansas	2	89
California	132	1219
Michigan	0	225
Nebraska	3	80
New Hampshire	1	57
Pennsylvania	3	406
Virginia	4	243
Wisconsin	5	162

You don't have to know anything about the incidence of deaf-blindness to see that these figures are unreasonable. The highest number for any state is 132 from California. Even if they were right, how could California have 132 and Michigan have none? It just doesn't work that way. There is no reason to believe that the condition of deaf-blindness is not normally distributed across all of the states in the same manner as the other types of disabilities. The figures here are so obviously wrong that printing them without explanation is inviting trouble.

In any state, the number of students receiving special education, is fairly consistent in relation to the total number of students that are enrolled in that state. This number is quite predictable—between 10% and 12%. In some earlier studies that we conducted, we determined that the incidence of deaf-blindness was probably around 2 in every 1000 special education students being served. This number is not precise, so we talk about an expected range based on a standard deviation we found in our sample. If our expected numbers are close, and the deaf-blind coordinators findings are getting very close, then one would expect to find approximately 10 thousand students who are deaf-blind, based on the nearly 5 million special education students served nationally.

We will be the first to tell you that we don't have complete diagnostic information on all 8500 students on the deaf-blind census. We are certainly pushing hard to get the additional information on all students so there will be no question about their eligibility to be classified as deaf-blind. In the meantime, if we are only 50% correct there are still considerably more students than the 1423 reported in the 15th Annual Report.

I want to emphasize that our purpose in identifying and classifying someone as being deaf-blind is for the sole purpose of trying to ensure an appropriate program for them. Such classification has *nothing* to do with creating separate classrooms or segregated programs or facilities. There is a national movement to do away with disability categories all together. The groupings would be based on educational need rather than labels. This would be wonderful. We could put our energies toward advocating for programs that were capable of offering instruction that takes into account the need to provide alternative strategies in both the auditory and visual modes. If these decisions are based on sound assessments, then we don't need labels, we simply need programs that have appropriate practices.

In the meantime, if we don't identify persons with these specific needs associated with the disability of deaf-blindness, they will likely go underserved. We can not allow our lawmakers to think that only 1400 children who are deaf-blind exist nationwide. Our system is not perfect but it is light years ahead of the procedures used to gather information for the Annual Report.

Reference:

U.S. Department of Education, Office of Special education programs. (1993) Fifteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: Author

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Family Fun Day

An Experience in Nature

Barbara Cook
Parent

The rain did not stop that Saturday in October. However, the leaves were at their most brilliant color as we gathered in northern Delaware to have fun. The weather did not dampen our spirits; in fact, it added to the day. The fire we built in the large fireplace of the lodge-like building of the Ashland Nature Center made us warm, cozy, and comfortable. Long, low windows allowed the magnificent fall surroundings to invade the room. The outside activities, of course, had to be scrubbed, but there were so many inside activities that the fun continued from 10 in the morning until 5 in the evening. At the end, many were reluctant to say good-bye. Families and extended families (teachers, aides, administrators, interpreters, helpers, etc.) and our children who are deaf-blind talked together, played together, and ate together. We stuffed scarecrows, painted T-shirts, painted faces, painted pumpkins (mostly natural materials were used), saw and touched a Native American Program on the Lenape tribe (excellent tactile material), and played games. Parents and school staff talked together while their children were delightfully engaged in activities with the assistance of others. How relaxing.

The highlight of the day was a presentation of wild animals—the beautiful white dove, the struggling alligator, the languid boa constrictor, the stately red-tailed hawk, the huge snapper turtle, the tree frog, and the toad. The children could see them or feel them or hold them and were not at all frightened (although some parents and staff seemed less inclined to touch).

At the end, singers from the Philadelphia Folk/Song Society delighted us with stories through song (wonderfully interpreted so all were able to understand). And finally, we were encouraged to sing along with many old favorites. Even the Nature Center Staff, who were fascinated at the obvious enjoyment of our children (who could neither hear or see), had a unique experience. A few modifications and some extra hands made it all possible.

Family Fun Day was made possible through the joint efforts of the Delaware Program for the Deaf-Blind and the Delaware Association of Deaf-Blind, Inc. (Parent Advocacy Group) and partially funded by the Hilton/Perkins National Program, through a grant from the Conrad N. Hilton Foundation of Reno, Nevada.

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A Guide for Presenters at Interpreted Conferences

Rhonda Jacobs and Richelle Hammett

(Excerpted and adapted from: *And Equal Access For All: Hiring a Qualified Interpreter vs. Ensuring Effective Interpretation* by Rhonda Jacobs and Richelle Hammett, 1994).

As you may be aware your presentation will be interpreted for audience members and participants who are users of a different language. In this case, that language will be either spoken English or American Sign Language (ASL), received either visually or tactually. Hiring a qualified interpreter does NOT, in and of itself, ensure that a presenter's remarks will be effectively interpreted to the audience.

Use the following key points as a guide to prepare your presentation for interpretation.

1 Have your presentation prepared ahead of time.

2 Send a copy of paper/outline of remarks well in advance of presentation to the interpreter coordinator and/or interpreters.

3 Set aside time to meet with interpreters before the presentation begins; discuss the presentation, background information, main points, goals/intentions, names and acronyms that will be used. Discuss various roles as applicable, such as interpreter-guide (with Deaf-blind[1] presenters), parallel platform interpreter/transliterator[2], and ASL to English ("voice") interpreter, and how these roles affect you.

4 If possible, plan to rehearse the presentation with the interpreters. Discuss pacing and pausing with the interpreters.

Working Together with the Interpreters

Remember, the interpreter is representing you, essentially "becoming you" for that period of time. The interpreter must have as much access as possible to what is going on in your thoughts—before going on stage. According to Danica Seleskovitch (1978), an internationally recognized authority on spoken language conference interpreting (Sorbonne, Paris), "Being mistaken about the speaker can. . . seriously impair one's understanding of an entire speech" (p. 26). For interpreters to speak/sign smoothly, they must know what you are going to say before you say it, why you are saying it, and what you want the audience to "bring home." "To understand the message, one must first understand the purpose" (p. 29). Also, interpreters are trying either to understand or to express your message in their second language, while essentially engaging in split-brain activity—expressing one thought while simultaneously listening to the next one.

Consider the following, all too common statements from presenters: "Don't worry, my presentation is only ten minutes," "I'll speak/sign slowly so you'll be able to catch it," or "Just slow me down anytime." These statements represent a central misunderstanding that speed or time is the interpreter's problem, when understanding the message is what is crucial. The point is that each of your thoughts and comments contain a wealth of background, knowledge and shared history. Interpreters are trying to capture that whole and see it from your perspective so that they may, first, understand it and, second, relay it to the intended audience, in order that they may best understand what you are trying to convey.

As Seleskovitch so aptly puts it,

> . . . let us imagine that an animal were to pass under our noses so quickly that we could not identify it. If we had not 'understood' what we had seen, would we be capable of describing the animal so that our listeners could recognize it even though we had not recognized it ourselves? . . . the interpreter who has not understood is as incapable of saying anything meaningful as the person who sees something move and, not knowing whether he has seen a snake or a mouse, will refrain from stating definitely whether he has seen one or the other.

1 We are using the convention established by some researchers and some members of the Deaf community of the capitalized "D" Deaf as opposed to deaf. Deaf refers to members of the Deaf or Deaf-blind communities who regard themselves as culturally and linguistically Deaf (i.e., users of American Sign Language). Although in this paper we refer to American Sign Language (ASL), and use the capitalized Deaf and Deaf-blind, the comments herein apply equally to those who use an English-based form of signing and/or do not regard themselves as culturally Deaf (Padden, 1980).

2 Parallel interpretation/transliteration refers to when the presenter is signing, while also having an interpreter on stage signing as well, either in ASL or an English-based sign variety.

Preparation is the key to whether or not the entire undertaking is successful. Even if the entire presentation is not fully prepared and typed out in advance, just telling the interpreter: "I will be talking about a chicken crossing the road, the point being to see if he gets to the other side; whether or not he makes it is dependent on three factors, A..., B... and C..." is immensely helpful to the interpreter. Otherwise, during the interpretation, the precious few moments that she or he should be devoting to picking just the right word, maintaining the proper affect, and doing a myriad of other tasks required of an interpreter, will instead be spent trying to figure out "was that a chicken or a duck? and why is it crossing the road? and what difference does it make anyway?" If you, the presenter, have informed the interpreter of these points prior to the actual presentation, the interpreter is then free to focus on the elements that make for a quality interpretation. He or she will represent you in a manner befitting the occasion while maintaining the integrity of your message.

"...written text read aloud...has only a minimal chance of being ... properly interpreted..."

The authors included the following excerpt for presenters who plan to read their papers at conferences—Ed.

A Note to Presenters Who Plan to Read Their Presentation

(Excerpted from: *Interpreting for International Conferences*, by Danica Seleskovitch, 1978).

Spontaneous speech produces about 9,000 words an hour. However rapid this pace may seem, it represents the speed of mental processes connected with speaking and it is therefore suited to the understanding capabilities of listeners of comparable intelligence and background. An interpreter listening to a speaker speaking off the cuff is therefore in a good position to understand, since he can turn words into ideas at the same speed as the speaker turns ideas into words; he is thus able to keep up with the speaker's delivery. In terms of a written text, the spoken language is more like a rough draft. By definition, a written text is intended to be read, and can be read over and over again, whereas the spoken word is meant to be heard once and once only.

A hybrid form of the two (the written text read aloud or recited from memory) means that the paper being presented has only a minimal chance of being fully understood when delivered and even less of a chance of being properly interpreted. . .

Interpreters are often called on to do "on sight" translations, i.e., to give an on-the-spot oral rendering of a written text as it is being read out at meetings. This amounts to asking them to convey messages which, because of their form and the way in which they are presented, are not amenable to interpretation at all and this at a speed of 200 words per minute, or 40 times faster than normal written translating work. This absurd state quickly reduces the interpreter to a state of mental and physical exhaustion; usefulness to the listener is practically nil, when compared to the service they are able to render when dealing with free speech. Placed in an impossible situation, he gives up trying to understand: He leaves his sentences unfinished, becomes breathless and frustrated, soothes his troubled conscience when he sees that his colleagues are managing no better than he, is happy to translate a word or two correctly here and there, curses the day he accepted that particular conference, leaves the booth as soon as the meeting is over and vanishes gratefully into the anonymity of the crowd. The best interpreters, however, those who have proved themselves worthy of the name, refuse to jeopardize their profession's reputation by working under these impossible conditions. They simply switch off their microphones.

The only possible solution to this serious problem is to give the interpreter the opportunity of thoroughly reviewing the documents which are to be delivered at a conference. He should be given a few days before the start of a conference to study and annotate the papers which he will be required to translate orally. In addition, a sufficient number of interpreters would have to be hired to staff the conference so that each one would have enough time, while his colleagues were at work in the booth, to go over the papers which come in at the last minute. This would mean that interpreters would be hired for a longer period of time, the number of days of paid preparation being equal to the number of working days of the conference; it would also mean doubling or tripling the size of the interpretation teams. (p. 134–135).

References:

Seleskovitch, D. (1978). Interpreting for international conferences. Problems of language and communication. S. Dailey & E. N. McMillan (Trans.). Washington, DC: Pen and Booth.

Padden, Carol (1980). The Deaf Community and the culture of Deaf people." In C. Baker, & R. Battison (Eds), Sign language and the Deaf Community: Essays in honor of William C. Stokoe. Silver Spring, MD: National Association of the Deaf.

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DB-LINK

Cruising the Information Highway

or How Can I Be In Two Places At Once When I'm Not Anywhere At All?

Randy Klumph
Technical/Dissemination Specialist
DB-LINK

At 4:30 on a Friday afternoon, the pediatrician delivered her diagnosis to the parents: The child had CHARGE Association. The parents had thought they would be prepared for this news. After all, their four-year-old had been medically fragile since birth, and it seemed the family was always adjusting to difficult news. However, this was the first time they had been given a name. Up until now their child has been described to them as developmentally delayed or disabled, or showing signs of progressive degenerative hearing/vision loss. Although the doctor was thorough in her answers to the immediate questions, it wasn't until the parents returned home that the majority of the questions began to form. By then it was too late for answers. Offices were closed, the doctor was off shift, and their rural library would be of little help. They would have to wait through what would now be a very long weekend to get the answers they needed.

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Most of us, when facing a crisis, want immediate answers to our questions. Information gives us a feeling of control; it allows us to make decisions and move forward in our lives. Information typically comes from our own formal and informal groups (e.g., friends, family members, parent groups, professionals, organizations). Our relationships to people and organizations are fundamental to the successful management of any crisis and they provide the cornerstone of our support structure. Today however, we can add yet another level of support to our list of resources. By taking advantage of technology we can access even more information, electronically, through commercial on-line services and computer bulletin board services (computer BBSs)[1].

Many of us have heard about the information highway, on-line services, and computer BBSs. Many of these avenues are immediately available to anyone who has a computer, a modem, modem software, a telephone, and a subscription to a commercial on-line service (e.g., CompuServe, SpecialNet, Prodigy) or access to a computer BBS (e.g., Disabilities Electronic Network). This article describes some of the electronic information avenues currently available, what you will need to get started, and whom to contact for more information.

What is the difference between an on-line service and a computer BBS?

On-line services come from "for profit" companies that charge their subscribers to connect to the service. Some charge by the minute, plus extra charges for accessing certain databases or special services. Others charge a flat monthly fee or a variable fee depending on the time of day the call is made (calls during normal business hours are more expensive with some on-line services). On-line services are more comprehensive than a computer BBS in the kinds of services and topics they cover. CompuServe for example, is the most comprehensive of the on-line services with over 600 topical areas or "forums." Some, such as Prodigy, are oriented more toward family interests. All on-line services and most BBSs also have electronic mail service (e-mail), allowing you to send and receive private messages electronically.

Computer BBSs are typically free or they charge a minimal annual fee, and they are usually staffed by volunteers. They are more specific in their subject matter and often have members who are from the same geographic location. The better BBSs however, are able to draw callers from all over the country who are willing to pay long distance charges in order to access timely and useful information in the libraries that are related to the BBS.

What's in it for me?

If you are in the business of gathering or disseminating information (e.g., research, information clearinghouse) or if you are simply a person like those mentioned above, who needs to find answers, you may wish to access the following topics. These are only a very small sample of the many electronic forums and databases that are available electronically, either through an on-line service, computer BBS, or subscription.

- Medicine
- Education
- Health
- Bibliographies
- Adoption Forum
- Financial
- SpecialNet Deafblind Bulletin Board
- Bioscience Documents from the BioSci Network
- Resource Directories
- Nutrition
- Law
- Disabilities Forum
- ABLEDATA
- Internet Deafblind Forum
- Family Medicine Discussion Archives
- Directory of Electronic Journals and Newsletters

Forums are like a combination electronic bulletin board and a meeting hall. In a forum, you will find other people with interests similar to yours—in agreement as well as with opposing views—covering a wide range of topics all related to the particular forum. Messages are posted onto the forum message area and are given a descriptive subject heading. Replies are added to the original message. Also in the forums are libraries where

[1] *For a detailed comparison of the five major commercial on-line services, their costs, and contact information, see PC MAGAZINE, March 15, 1994, Vol. 13, No. 5.*

participants have placed files of information they have found useful and are making available for others to use (e.g., newsletters, special equipment catalogues, research papers). Most forums have a conference area where "attendees" can ask questions and exchange ideas with invited experts, or get together for group discussions.

Database services differ somewhat from forums since they are for search and retrieval only and do not typically have a forum area. They are usually maintained by a government or other nonprofit agency. As with computer BBSs, some are free, and some are not. There are as many database services as there are disciplines. Some database services maintain only historical information; some maintain current information, and some maintain both. Finding the right one is not as difficult as it might seem unless your topical interest is very obscure.

What equipment do I need?

Hardware/Software:

- Computer
- Modem
- Telephone line
- Modem software

There are many modem software packages available that vary in their level of required skill. Some software packages are specifically designed for a particular on-line service. The CompuServe Information Manager for example, was developed specifically for easy connection and navigation in CompuServe and is for use only on CompuServe. MOSAIC is another navigation software package for use on the Internet. Still other software programs such as Qmodem, Procomm, or Microphone (most manufacturers include modem software with their modems) will allow you to connect to *any* on-line service or computer BBS. Beyond that, the only other item you will need is a healthy curiosity.

What if I am a technical novice?

If you are a technical novice and need assistance selecting or setting up the correct hardware and software, there is help. Most of us know someone who is "into" computers. Invite this person over for dinner and an evening of technical assistance. Just make sure they know what is in store for them. Most "techies" enjoy helping new users enter the world of electronic communication. They have found it to be an exciting medium and are eager to share their enthusiasm and expertise. If you do not know anyone who fits this description, then consider a class at a community college. In addition, there are many books and magazines available covering all aspects of this topic. Many of the on-line services have voice phone numbers you can call for help with your initial setup questions. Once you have the equipment and are connected to a BBS or on-line service you will find an army of people on-line who are all too happy to assist you. If you want to quickly expand your professional and personal network, then on-line services and computer BBSs provide opportunities to reach into the vast network of parents, professionals, individuals and organizations that are part of this growing technology.

What If This Isn't For Me?

If you choose not to participate in these services, the technology can still be available to you by using the services of organizations who do use it and letting them use their expertise to get the information you need.

For example, at DB-LINK, gathering information (from the obscure to the familiar) and delivering this to the consumer is a daily occurrence. Through the use of computers, modems, and by utilizing the technical expertise of various staff, we have developed access to the global information warehouses that exist electronically. We can search MEDLINE for article citations and abstracts that are indexed from over 4000 medical journals. We can access the NORD database (National Organization for Rare Disorders) for a description of symptoms, treatments, and organizations for a specific syndrome. We can search our own Catalogue and Resource Databases for bibliographic and referral resources. These are just a few of the avenues available that allow us to meet the needs of the people who call.

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At 10:30 Friday evening the parents logged onto CompuServe and conducted a search of the NORD Database and PaperChase (the MEDLINE database of references to biomedical literature). After saving the information for later reading, they found forums discussing issues related to people who are blind and people who are deaf. They were able to leave unanswered questions on various bulletin boards. When they "checked their mail" at 7:00 a.m. the next morning, they had four responses. At the 6:00 p.m. mail check they had another seven responses. By 11:00 a.m. on Sunday, "conversations" were occurring regularly as people responded to their need for information. Not all their questions were answered. In fact, they learned they had even more questions, many that would require the resources of a national organization, such as DB-LINK. But they also found that their familiarity with the electronic information networks had given them an advantage in developing their own resources. They were given the names of organizations to contact, books to read, resources in their area, and parent support groups. They also learned about their own coordinator of state and multi-state projects under Section 307.11 and how important this person would become in their lives. They were able to receive answers to their pressing questions. They felt more in control, as their lives moved forward.

To contact DB-LINK:

DB-LINK
345 N. Monmouth Ave
Monmouth, OR 97361
voice (800) 438-9376
TTY: (800) 854-7013

SpecialNet: trd
CompuServe: 73324,2140
Internet:
leslieg@fsa.wosc.osshe.edu

For more information on the services mentioned in this article contact:

CompuServe
P.O. Box 20212
Columbus, OH 43320
voice: (800) 848-8199
fax: (614) 457-8149

Disabilities Electronic Network (DEN)
Tom Bengaff, SysOp
171 Atlantic Street
Hackensack, NJ 07601
voice: (201) 342-6984
BBS dataline: (201) 342-3273

Internet Deaf-Blind Forum
Bob Moore
Stroke Program, Center on Aging - Univ. of Kentucky
Lexington, Ky 40536
voice: (606) 233-5760
fax: (606) 258-2866
str002@ukcc.uky.edu

National Clearing House of Rehabilitation Training Materials (NCHRTM)
voice: (800)-223-5219
voice: (405) 624-7650
fax: (405) 624-0695
BBS and Materials Database (dataline): (405) 624-3156

Prodigy
Prodigy Services Company
P.O. Box 791
White Plains, NY 10601
(800) 776-0845

SpecialNet
GTE Education Services
5525 Mac Arthur Blvd.
Suite 200
Irving, TX 75038
(800) 927-3000

DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind) is funded through Cooperative Agreement No. HO25U20001 by the U.S. Department of Education, OSERS, Special Education Programs. The opinions and policies expressed by DB-LINK do not necessarily reflect those of the U.S. Department of Education.

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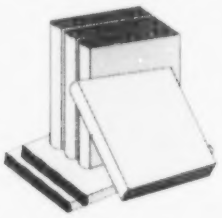

For Your Library

Persons Handicapped by Rubella

By Jan Van Dijk (with cooperation of Ruth Carlin and Heather Hewitt) (1992).

This publication discusses relevant studies in the literature relating to children with congenital rubella, and provides parents and professionals with the latest information on appropriate education and management strategies.

180 pages, Cost $36.00

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Play and Recreation for Individuals with Disabilities

Susan J. Grosse and Donna Thompson (Eds.)

Practical and detailed suggestions on involving individuals with disabilities in recreational activities. Suggestions for evaluating and adapting equipment and dealing with specific conditions are given. Many of the chapters contain the names of organizations and bibliographic references.

139 pages, Cost: $ 23.95 (+ $2.50 shipping and handling)

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Adapted Physical Activity Council of the Association for Research, Administration, Professional Councils and Societies.
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Reston, VA 22091
(800) 321-0789

Directory of National Information Sources on Disabilities - 5th Edition (1992)

National Institute on Disability and Rehabilitation Research

This directory identifies and describes organizations that supply disability related information, referral, and direct services on a nationwide bases.

555 pages, Cost: $ 10.00 (for shipping and handling)

To order contact:
NARIC
8455 Colesville Rd. Ste. 935
Silver Spring, MD 20910-3319
(800) 346-2742 (voice and TTY)

Resource Directory 1993 - 1994

HEATH Resource Center

The HEATH Resource Directory is a biannual selection of resources in the postsecondary education and disability fields. Many of the listed organizations can respond to questions about an individual's own situation. Each section lists additional resources (e.g., books, directories, magazines) and/or organizations.

39 pages, Cost: Free

To order contact:
HEATH Resource Center
One DuPont Circle, Ste. 800
Washington, D.C. 20036
(800) 544-3284 (voice and TTY)

Deaf-Blindness: National Organizations and Resources. Reference circular No. 93-1

Library of Congress, National Library Service for the Blind and Physically Handicapped. Washington, DC: January 1993.

The circular includes information on areas of service: rehabilitation, education, information and referral, recreation, sources for adaptive devices and products, and a bibliography. It is intended for use by people who are deaf-blind, family members, professionals, and the general public.

24 pages, Cost: Free

To order contact:
National Library Service for the Blind and Physically Handicapped
Library of Congress
Washington, D.C. 20542
(202) 707-5100

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National Family Association for Deaf-Blind

On June 27, 1994 National Parent Network (NPN) will become National Family Association for Deaf-Blind (NFADB). Tremendous growth in the numbers of families desiring information and connection to each other caused NPN to re-evaluate its advisory role and establish a design team to create a more formal, structured, and operational national organization.

Parents representing individual family members and state organizations around the country have adopted this new title to support and advocate for people who are deaf-blind and the members of their families. The founding members of NFADB have adopted the following philosophy statement: "Individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community." To support this mission, NFADB has targeted a wide range of activities including:

- advocating for all persons who are deaf-blind regardless of age or ability
- supporting national policies that benefit people who are deaf-blind
- helping to facilitate the founding and strengthening of family organizations in each state
- being a resource group, sharing information, and providing referrals
- collecting data, expertise, and resources that are in unity with NFADB's philosophy to assist families
- assisting states with various issues
- collaborating with professionals
- serving as a public information resource

In addition to the organizations' officers, NFADB will have a parent representative in each of the 10 Helen Keller National Center regions of the country. NFADB's officers and regional representatives are:

President	Joyce Ford
Vice-President	Mary O'Donnell
Secretary	Pat McCallum
Treasurer	Mary Lou Guisinger
Region One	Karen Norwell
Region Two	Clara Berg
Region Three	Barbara Caudill
Region Four	Brenda Weaver
Region Five	Peg Pedresen
Region Six	Janet Stevens
Region Seven	To be announced
Region Eight	Alan Wahl
Region Nine	Barbara Ryan
Region Ten	To be announced

Parents of children who are deaf-blind share common issues. A parent of a 24-year-old who has congenital rubella syndrome said, "I have been ignored, pushed aside, or last in line. What a family organization means to me is hope, support, information, and encouragement. I am no longer alone. We are everywhere!"

For more information contact:

NFADB
111 Middle Neck Rd.
Sands Point, NY 11050

(800) 225-0411 ext 275

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AADB 1994 National Convention

The American Association of the Deaf-Blind is a national consumer advocacy organization with over 600 members. AADB is organized for the purpose of advancing the economic, educational, and social welfare of persons who are deaf-blind. One of the highlights for this organization is its annual convention.

The convention offers a series of workshops, often held by individuals who are deaf-blind, and daily tours of places of local historical and cultural interest. This year's theme is **"Caring for Ourselves: Facing the Changes and Challenges."** This is an opportunity for individuals to interact with each other on an educational and social basis.

The convention is open to everyone, including individuals who are deaf-blind, friends, families, and professionals. Interpreters will be provided.

The 1994 convention will be held June 11–17 at the University of North Carolina, Greensboro. The deadline for registration is June 1, 1994.

For more information contact:

AADB 1994 Convention
814 Thayer Ave Suite 300
Silver Springs, MD 20910

TTY: (301) 588-6545
fax: (301) 588-7505

We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.

Traces

Regional Reports

FLORIDA

During the needs assessment process for Florida last year, it became apparent that the larger community of service providers (e.g., vocational teachers, rehabilitation counselors) needed to be made aware of possibilities in the area of transition for individuals who are deaf-blind. It was decided that a statewide conference of the Council for Exceptional Children Division on Career Development would provide an appropriate audience.

Mike McCarthy, from Missouri, presented a small group session titled, "Is There Life After School for Individuals with Deaf-Blindness?" He provided examples of how individuals who are deaf-blind can live and work in their home communities after graduation if the transition has been planned enough in advance to secure appropriate support services. He presented strategies for collaboration to secure these services and cited the implications for "Individual Transition Planning" and "Personal Futures Planning."

In addition, Mr. McCarthy was asked to give the conference wrap-up luncheon speech. He stressed that it is important to always remain person-centered, and he recounted accomplishments of individuals whom he has known who are deaf-blind. At the end, several participants noted that the entire conference was worth attending because they heard about real people who are deaf-blind who are successfully participating in their communities.

For additional information contact:
Anita Briggs
TRACES South Central Regional Coordinator
(904) 840-7147.

ILLINOIS - Establishing Local, Functional Assessment Teams

On October 18 and 19, 1993, the Illinois Deaf-blind Project, in collaboration with Helen Keller National Center for Deaf-blind Youths and Adults (HKNC), and Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments (TRACES), co-sponsored a conference titled "Training of Trainers: Functional Hearing and Vision Assessment Strategies for Individuals with Deaf-Blindness." The conference was held at the Philip J. Rock Center and School in Glenellyn, Illinois. The purpose of the conference was to provide inservice education to a team of specialists who will then provide support to professionals who serve individuals who are deaf-blind within local communities. Specifically, the professionals will be taught to perform functional vision and auditory assessments. Flo Peck, Low Vision Education Specialist from the Perkins School for the Blind, and John Mascia, Coordinator of Audiological Services from Helen Keller National Center, were the featured presenters.

Ongoing data collection by those who attended the conference will be recorded and analyzed by the Illinois Deaf-Blind Project Coordinator in order to evaluate the effectiveness of local service delivery. Data will include (a) the number of informal vision and/or hearing screenings; (b) the number of inservice training sessions to colleagues; and (c) the number of newly identified children who are deaf-blind. We congratulate all of those who worked so hard to establish this program.

For additional information contact:
Tina Dorsey, Chief Administrator
Philip J. Rock Center
(708) 790-2474
or
Margie Briley
TRACES
University of Pittsburgh
(412) 648-1424

Great Lakes Area Regional Center for Deaf-Blind Education

As a result of a needs assessment survey sent to educators, related services providers, and families of children and youth with dual sensory impairments, the Great Lakes Area Regional Center for Deaf-Blind Education has initiated a goal to focus on the development of assessment guidelines. A set of guidelines is currently being developed to address the following age levels: early childhood, school-age, and transition to adult life. The authors are (respectively) Ellin Siegel-Causey, June Downing, and Jane Everson. While the manuals are in different stages of development, each incorporates input from colleagues, service providers, and families. As part of the development stage of the manuals, a training workshop is utilized to field test the assessment processes outlined in each manual. This activity represents a collaborative effort between the state and multi-state projects under Section 307.11 in Ohio, Wisconsin, and Pennsylvania;

the Helen Keller National Center Technical Assistance Center; and the expertise of the individual authors, reviewers, and workshop participants. As completion of the manuals approaches, a wider dissemination plan is being discussed.

For additional information contact:
Emily Taylor-Snell
Project Coordinator
GLARCDBE
(614) 785-1163

NEW YORK

The New York State Technical Assistance Project (NYS/TAP) has entered its second year under the leadership of Project Director Mady Appell and Project Co-Director Carole Gothelf. Located in the Developmental Disabilities Center of St. Luke's Roosevelt Hospital Center in New York City, NYS/TAP is committed to supporting parent-professional partnerships, building systems that are responsive to the needs of the people they serve, and delivering the technical assistance needed to ensure appropriate services for children and youth who are deaf-blind.

During the first year of the project, NYS/TAP has been working toward achieving full partnership with the New York Parent Network, Inc. (NYPN), a dedicated group of parents and relatives of persons who are deaf-blind. These people have drawn together to establish a supportive network through which they can share experiences and knowledge, educate others about the needs of their families, and advocate for community services to meet their needs. The NYS/TAP Family Specialist and the President of NYPN presented a poster session at the 1993 TASH Annual Meeting entitled "Parent-Professional Partnerships in New York State." These two projects are fully committed to collaboration and cooperating with families and service providers in order to establish a system in which all children in New York who are deaf-blind and their caregiving families can have their needs appropriately met. The partnership ensures that every group is represented and that opportunities are provided for expression of every viewpoint.

Additionally, NYS/TAP and NYPN have forged reciprocal relationships with the New Jersey Technical Assistance Project and PRISM (New Jersey's statewide parent organization that supports individuals with visual and hearing impairments and multiple special needs and their families).These four projects are now planning their second annual Summer Institute. This collaborative effort grows from the idea that knowledgeable parents and professionals working in unison will ensure appropriate programs for children and youth who are deaf-blind and will be the most effective agents for systems change.

Another important focus for NYS/TAP during the past year has been to obtain an accurate child count. To achieve this, the NYS/TAP Project Coordinator has developed a computerized system to track each eligible individuals in New York State. This system creates a comprehensive database and, provides the statistical analyses necessary for immediate and long-term planning. The computerized system includes an automated annual follow-up for each individual, and a resource directory of programs serving those who are deaf-blind. As of November 1993, approximately 500 eligible children have been identified and registered; efforts to locate eligible children continue, with the expected total likely to be double the current figure.

For additional information contact:
Douglas Hegley
Project Coordinator
(212) 523-6230

Clara Berg
Family Specialist
212) 523-6230

or
Cheryl Kennedy
TRACES Project Northeastern Regional Coordinator
(412) 648-7176

ALASKA

Usher Syndrome is a genetic disorder involving the loss of both sight and hearing. A sensorineural hearing loss generally is evident at birth or shortly thereafter, while progressive loss of vision due to Retinitis Pigmentosa (RP) begins later in life, usually before adolescence.

It is estimated that 3% to 6 % of people who have a hereditary hearing loss have Usher Syndrome. Moreover, Usher Syndrome accounts for more than 50% of all cases of deaf-blindness, with 94 thousand estimated to be affected in the United States.

Several tests are used to determine if a person has RP. The most definitive test is electroretinography (ERG), with an accuracy of about 95%. Screening can determine an individual's disposition toward Usher Syndrome.

The Alaska Services for Children and Youth with Dual Sensory Impairments Project (ADSI) is developing a statewide screening process for early identification of individuals who are at risk. The initial step of this process has been completed with the development of a brochure providing comprehensive information regarding Usher Syndrome, techniques for screening, and available resources. The second phase of the process is to train educational personnel so that they may refer individuals for an ERG. The training is scheduled to occur this spring.

For additional information contact:
Sara Gaar
Program Supervisor
(907) 562-7372

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